Palliative care

Concepts and ethics

The study of this thesis was performed in the Research Institute Evidence Based Practice (EBP), which participates in the Netherlands School of Primary Care Research (CaRe), acknowledged in 1995 by the Royal Dutch Academy of Science (KNAW).

Palliative care

Concepts and ethics

Een wetenschappelijke proeve op het gebied van
de Medische Wetenschappen

Proefschrift

ter verkrijging van de graad van doctor
aan de Katholieke Universiteit Nijmegen,
volgens besluit van het College van Decanen in het
openbaar te verdedigen op woensdag 20 juni 2001,
des namiddags om 1.30 uur precies

door

Marinus Johannes Petrus Antonius Janssens
geboren op 19 oktober 1969
te Waalre

Promotor:

Prof. dr. H.A.M.J. ten Have

Manuscriptcommissie:

Prof. dr. B.J.P. Crul
Prof. dr. D. Clark (University of Sheffield, United Kingdom)
Prof. dr. P. Schotsmans (Catholic University of Leuven, Belgium)

Acknowledgements:

I am grateful to the Commission of the European Communities for funding the *Pallium* project of which this study forms a part.

I am grateful to the *Radboudstichting* and to the *Integraal Kankercentrum Oost* for the financial support for the publication of this study.

ISBN: 90 373 0569 5
Published by: Nijmegen University Press, Nijmegen, 2001.

Cover:
Sunset in Scotland. Photography by Britt van den Akker

"'Hij wees naar zijn mond en daarna naar zijn televisietoestel. Begrijp jij wat hij daarmee kan bedoelen?'
'Dat is zijn televisietoestel niet!' – Hij begon hard te lachen. 'Dat is de hemel! Hij wil dood! Hij wil dat je hem wat geeft om er een eind aan te maken!' "

(Uit: J.J. Voskuil, Het bureau 4, p. 53)

CONTENTS

INTRODUCTION

INTRODUCTION

1. Palliative care in focus

Simple questions hardly ever allow for simple answers. The main question of this thesis is simple: what is palliative care? As will be shown throughout the following chapters, the more one reflects about this question, the harder it becomes to answer it. Palliative care is a concept that is more ambiguous, less clear and less unitary, than is often presented in the literature.

If one examines the evolution of palliative care in the last three decades, it is safe to conclude that this ambiguity of the concept has increased and is still increasing in the context of recent developments. As long as palliative care was identified as hospice care, its demarcation from other medical practices was rather unproblematic. In fact, hospice caregivers chose to leave the formal health care system, take distance from it, out of a moral discomfort with the way dying patients were approached in hospitals. Thus, separate institutions were established situating themselves in a specific tradition of earlier hospices (Clark and Seymour, 1999; Humphreys, 2000). The modern hospice movement wanted to show that when curative treatments have failed, and when life prolonging measures are no longer feasible, there is still a lot that can be done to provide relief to the dying. The message that 'nothing can be done anymore' was unheard of in hospice practice. Apart from the firm organisational link of early palliative care with hospice buildings, the hospice concept itself was relatively univoque, based as it was on a solid consensus among those providing care in the hospices. Four aspects of the concept of hospice merit attention. First, the hospices intended to provide care for the dying. Hospice care was identified as terminal care and thus, its scope was limited. Second, hospice care in the late 1960s was mainly associated with cancer care. It assumed a progressive disease trajectory which would in its far advanced stage unavoidably lead towards death within a limited time span. Third, even though hospices were open for all patients, they were all based on Christian values and ideals. And fourth, related to these values, there was a solid consensus regarding the ethical norm that euthanasia should not form a part of hospice care, whereas at the same time more and more voices pleaded for a legalisation of euthanasia in British society.

The paradox of the hospice movement is that, while it separated from the mainstream health care system, the idea has always been to re-integrate its philosophy into the same mainstream health care system. Knowledge that

originated from research in pain and symptom management had to be adopted by physicians caring for their dying patients in hospitals and nursing homes. New attitudes regarding the acceptance of human mortality were to re-integrate. The same goes for psychosocial and spiritual aspects of care which were absent in medicine. While many hospice institutions were established, caregivers in these institutions did not stop to stress that hospice is first and foremost a philosophy, not an institution.

Thus, when the hospice movement gained international recognition, it was not difficult to imagine that 'hospice' became organised in other institutional forms than the separate hospice building. In 1975 for instance, Balfour Mount founded a hospice unit in the Royal Victoria Hospital in Montreal, but since the term 'hospice' carried negative associations in the French language, he proposed the term 'palliative care' as an alternative (Saunders, 1996). When the first European palliative care unit in Sweden began in 1977, it took the form of a hospital-based home care service (Valverius, 1999). Two years later, a Swedish government report took a stand against the opening of hospices as the solution to improving care for the dying. In 1980, the first palliative home care services were established in Italy (Privitera, 1999). In 1983, the first palliative care unit in Germany was situated on the top floor of a University Hospital (Illhardt, 1999). Also in Spain and Belgium, the first palliative care services were not developed in separate institutions but in hospitals (Gracia, 1999; Broeckaert, 1999). And in the Netherlands, important initiatives to improve terminal care were taken within the field of nursing home medicine (Janssens and Ten Have, 1999).

Thus, palliative care in many European countries was integrated in the mainstream health care system from the outset, even though many pioneers had received their education in hospices in Great Britain. The justification for the establishment of separate institutions, namely the insufficiency of care for the dying in the mainstream health care system, became more and more challenged. Instead, the integration of hospice, conceived of as a philosophy, in a variety of medical practices was aimed at.

While in countries such as Spain, Belgium and Sweden a consensus existed that the development of palliative care would not profit from the establishment of separate institutions, in other countries, notably the United Kingdom, Germany and the Netherlands other forces were also at work. In the context of increasing involvement of the national governments, together with the involvement of medical associations, these forces feared that palliative care would become medicalised and bureaucratised. In the context of health care policies stressing cost-effectiveness, evidence based models of practice, and

efficiency, they claimed that the original hospice philosophy would be in danger of becoming neutralised. Especially in the UK, notions such as medicalisation, bureaucratisation, routinisation, secularisation have been confronted with the early ideals of the hospice movement (Clark, 2000). Today however, most official European health care authorities stress the necessity to integrate palliative care in the mainstream health care system.

The integration process of palliative care that is still going on was foreseen and hoped for by the early modern hospice movement. It can however not be denied that this integration process has had substantial impact, not only on the organisational forms in which palliative care is given shape, but also on the philosophy of the hospices. First, the identification of palliative care with the terminal phase of illness is rejected now by a majority of palliative care practitioners who hold instead that palliative care starts from the time of diagnosis (see chapter 3). Second, the identification of palliative care with cancer care is put more and more under critique. It is widely acknowledged that patients suffering from Alzheimer's disease, heart failure, aids, multiple sclerosis and other chronic diseases have been neglected by palliative care practitioners for too long. Third, the Christian values underpinning the philosophy of the hospices can no longer be taken for granted as in the context of the health care systems palliative care is considered to be a secular discipline. Fourth, the ethical norms are more and more subject to debate. In the Netherlands, the majority of physicians providing palliative care accept euthanasia as a means of last resort and in many other countries, there is no consensus that euthanasia should be excluded from palliative care (see chapter 8). Debates on the validity of the doctrine of double effect, withholding and withdrawing life prolonging treatment, terminal sedation, research in palliative care have intensified during the last three decades and a consensus cannot be expected.

The integration process of palliative care into the mainstream health care systems has made the concept of palliative care ambiguous and ambivalent. The scope of palliative care is unclear. Its demarcation from other medical practices has become problematic. The values underpinning the concept of palliative care are now under debate as well as the ethical norms for good palliative care practice.

In this thesis, the concept of palliative care is described, analysed and evaluated, especially with regard to the moral issues that arise in palliative care.

2. The European *Pallium* project on palliative care ethics

The assumption that the concept of palliative care is ambiguous and in need of critical analysis was the motive to initiate the European *Pallium* project on palliative care ethics. With financial support from the European Commission, 35 experts in the field of palliative care from Belgium, Germany, Italy, the Netherlands, Spain, Sweden and the United Kingdom were brought together. The project started in March 1998 and was completed at the end of February 2001.

The *Pallium* project set itself four aims, running parallel with four phases:

1. To examine and compare the organisational forms of palliative care;
2. To analyse and compare the concepts of palliative care;
3. To explain the relationships between concepts and institutional heterogeneity of palliative care
4. To analyse and evaluate the ethical debates on palliative care and the moral implications for the further development of palliative care.

The research of this thesis was carried out in the context of the *Pallium* project. All chapters contribute to one of the four aims of the project. Chapter 4 was written in close co-operation with 8 project participants. Many chapters have benefited from the input of colleagues. The confrontation of various concepts of palliative care with one another provided insight into the particularity of the concept prevailing in a specific country. At the same time, the comparative character of the project was helpful in gaining a sharper, more critical view on the concept prevailing in one's own nation. Unexamined self-evidences were brought to the surface and became problematic in the light of concepts within which these self-evidences are non-existent or under debate. Through international comparison, aspects of palliative care that had been left unattended in the context of specific national debates, could be re-introduced. The concept of palliative care thus became more problematic on the one hand but richer on the other hand. The surplus value of the European *Pallium* project had everything to do with its comparative character through which different concepts of palliative care were confronted with one another.

3. Objectives of the study

The research has been carried out at a time in which the understanding of the concept of palliative care is undergoing important changes. The concept is increasingly associated with a variety of meanings. On the one hand, it is no

longer possible to argue for a single, 'true' concept of palliative care. On the other hand, if one follows the literature on palliative care, the meaning of the concept is often too easily taken for granted. At the most, a definition serves to identify what is meant with palliative care. In other words, even though this thesis does not argue for one 'true' understanding of palliative care, it does intend to explicate the various meanings that the concept of palliative care carries with it since these meanings often remain hidden under the surface. The first objective of this thesis has therefore been to explore, clarify, analyse and evaluate different understandings of the concept(s) of palliative care.

In the course of the study, it has become clear that clarification and analysis of the concept of palliative care is for a significant part an ethical enterprise. The demarcation of palliative care from other medical practices requires ethical research. Moral notions that are used in the debates on palliative care are indicative of a certain specificity of palliative care, either because they differ from notions that are used in the context of curative medical practices, or because they are attributed a specific meaning in the context of palliative care. However, if one follows these debates on palliative care, critical analysis of these notions remains absent. Often it remains unclear what is meant with 'quality of life'. The notion of autonomy is uncritically adopted from a form of medical ethics that is primarily associated with curative care. The notion of pain is still approached with a medical gaze. Many other examples of notions that are insufficiently reflected upon can be given. In this thesis, a number of notions that are used in the debates are analysed from a theological or philosophical perspective. The claim is that philosophical or theological theory can bring aspects of notions to the surface that have been forgotten by a dominant, action oriented form of medical ethics. The second objective of the thesis has thus been to provide new perspectives on palliative care by analysing moral notions that are used in the debates on palliative care from a theological and philosophical perspective and to introduce practically relevant notions that have been forgotten.

This second objective also has consequences for the debates on medical decision-making at the end of life in palliative care. Aspects that have been underestimated so far are proposed again and the particularity of dominant discourses is brought to the surface. For instance, up until recently the Dutch debate on euthanasia has been mainly concerned with data, procedures and guidelines. Now that palliative care is more and more at the focus of interest in the Netherlands, new perspectives on euthanasia emerge. The vast majority of

Dutch physicians agree that good palliative care can prevent requests for euthanasia. Alternative modalities of palliative care are more under attention. At the same time, the issue of euthanasia is still considered a taboo by many palliative care practitioners from other countries. An open, international debate on euthanasia is absent. Consequently, the Dutch debate on euthanasia needs to be broadened, drawing attention to possible alternative palliative modalities. Furthermore, tools need to be provided for an open and critical international debate in which different opinions are allowed to co-exist.

4. Outline of the thesis

Chapter 1 provides a summary analysis of the ethical theory that is adopted in this thesis. It will be argued that medical ethics, in order to be relevant for palliative care practice, should re-orient itself towards its theological and philosophical roots.

It is far from accidental that the origins of modern palliative care and the origins of modern medical ethics can be traced in the same period of time, namely at the end of the 1960s. After all, both movements have come forth out of moral discomfort with a health care system that primarily focused on cure and life prolongation, if necessary with the means of disproportionate technological interventions. However, whereas the hospice movement stressed the importance of pain and symptom control and of psychosocial and spiritual aspects of care this was not the main goal of medical ethics. The moral discomfort of the new discipline of medical ethics related to the paternalistic attitude of physicians. In the context of the technological possibilities of medicine, it was noted that the application of medical technology could under circumstances be more harmful to the patient's well-being than beneficent. And if that is so, the decision to apply such interventions should no longer be made by physicians but instead by patients themselves. The power of the physician to administer medical treatment where and whenever possible should be handed over to the patient. The principle of autonomy thus became foundational for modern medical ethics. In the 1970s medical ethics developed into a principlist action-oriented theory which served to solve moral dilemmas in medical practice. The philosophical and theological roots of medical ethics were abandoned. Medical ethics came to be seen as a distinct field of science since it had adopted the theoretical framework of the medical sciences.

In chapter 1, this approach of medical ethics is criticised and it is argued that medical ethics should not be seen as a distinct science but as a part of

philosophy or theology. Instead of solving moral problems, the first task of medical ethics in general and of palliative care ethics in specific should be to listen closely to what is said and written by the caregivers in the field. What notions are dominant in the debates on palliative care? What is the philosophical and theological meaning of the notions that are used? What notions are not used? In critically analysing what is said, and especially what is not said, a richer understanding of palliative care practice evolves and orientations for concrete action can emerge. The concept of medical ethics that is used in this thesis is solidly based on its philosophical and theological roots, holds a certain critical distance from palliative care practice, and claims to have more practical relevance than the dominant 'problem solving' conception of medical ethics.

In chapter 2 conceptual and ethical aspects of palliative care are examined from an historical point of view. The modern hospice movement that originated in the 1960s situated itself in the tradition of hospices that were established in the early Christian era to provide shelter for pilgrims who were on their way to the holy places. According to Cicely Saunders herself, the principles of the modern hospice movement are an extension of the principles of these early hospices (Saunders, 1994a). Furthermore, the British hospices that were established after 1967 were clearly situated in the tradition of the pre-modern hospices which originated at the end of the 19th century and at the beginnings of the 20th century. These hospices were specifically designed to provide care for the dying. Insight in the historical roots of today's palliative care reveals continuities but also discontinuities. The ambivalence and heterogeneity of the organisational, conceptual and ethical aspects of palliative care can be explained by the integration process that is currently taking place in many European countries. Problems regarding the demarcation of palliative care from other medical disciplines are analysed. It is argued that the norm 'not to hasten death' in palliative care should be subject to a critical, open debate. Normative statements require arguments to support them.

Chapter 3 aims to identify and analyse the views of professionals working in the field of palliative care on the concept and ethics of palliative care. It results from a large scale questionnaire study among more than 2000 palliative care experts. The assumption that palliative care is subject to change is corroborated. The opinion that palliative care should be fully integrated with the mainstream health care system is held by a majority of respondents whereas at the same time concern is expressed about the specificity of the moral values underpinning palliative care. Integration of palliative care without the medicalisation of its philosophy seems to be a challenge for the future development of palliative care. Medicalisation threatens the essence of palliative

care; an essence which relates to the provision of total care in which the medical, psychological, social and spiritual realms of care are of equal importance.

Chapter 4 analyses the various debates on palliative care in the Netherlands. On a fundamental level there is a consensus about the basic characteristics of palliative care. However, if one follows the debates in the literature, disagreements occur relating to the scope of palliative care, the organisational structures most suitable to provide palliative care in, the moral values underpinning palliative care, and the historical development of palliative care in the Netherlands. Also the euthanasia debate, so typical for the Dutch context, is not only concerned with the morality or immorality of ending someone's life. It will be indicated that the Dutch euthanasia debate cannot be understood without taking the quality of palliative care provision into account. A lot of disagreements can, at least for an important part, be clarified by looking at the political agenda of the participants. If one leaves out the external goals, such as political interests, status and competition, there may be more consensus on what palliative care is than appears from the debates. The debate on palliative care in the Netherlands should therefore be re-oriented towards the internal goal of palliative care: the quality of life of the patient and his or her loved ones.

Chapters 5 and 6 analyse notions that are used in the literature of palliative care. Chapter 5 is a phenomenological analysis of the notion of pain. Whereas pain in the context of medicine used to refer to a bodily injury that has to be removed as soon as possible, phenomenology has depicted pain as an experience. The meaning of pain, from religious, metaphysical, social, moral or artistic points of view has been left unconsidered within the biomedical paradigm. The introduction of the concept of total pain by Cicely Saunders has also come forth out of a critique of this biomedical paradigm. However, even though in theory the multi-dimensionality of pain is acknowledged, medical practice is slow to adapt to the new challenges lying ahead. Moreover, it can be questioned to what extent the concept of total pain still carries traits of the old Cartesian biomedical paradigm. Distinctions between medical, psychological, social and spiritual aspects of pain may lead to a fragmentation of care in which the physician is still pre-occupied in removing physical pain. New multi-dimensional perspectives on pain that allow for other ways of dealing with pain than only medical intervention are now beginning to emerge.

Whereas in chapter 5 new perspectives are introduced on a notion that is often used in palliative care practice, chapter 6 draws attention to three notions that are less frequently used in palliative care: the notions of medical restraint, authenticity and hope. It is argued that these notions can reveal important

aspects of the medical, psychosocial and spiritual realms of palliative care. In palliative care, the boundaries of medicine are acknowledged. At a certain stage there comes a time in which the quality of life of the patient becomes the sole criterion for medical decision-making. This acknowledgement, together with the acknowledgement that psychosocial and spiritual elements of care are just as important as medical aspects is illuminated by the notion of medical restraint. And instead of the notion of autonomy, that is intrinsically connected with the dominant conception of medical ethics, the notion of authenticity is proposed because it is better equipped to include elements of fragility and dependency; elements that are characteristic for the *condition humaine* in general but especially for the condition the dying are in. It is argued that, in order to render account of solidarity, the notion of authenticity should be paired with the notion of hope. Hope should not necessarily refer to obtainable objects. Hope is also connected with eschatology, i.e. with questions regarding what is of ultimate importance to us in the face of death.

Chapter 1 analyses the ethical theory adopted in this thesis. Chapters 2, 3 and 4 examine conceptual aspects of palliative care and clarify the ethical and philosophical debates on palliative care. Chapters 5 and 6 analyse notions that are used in those debates. Moreover, forgotten aspects of those notions are proposed in order to broaden their meaning for palliative care practice. Finally, chapters 7, 8 and 9 deal with moral dilemmas in palliative care. None of these three chapters purports to solve the dilemmas that occur in palliative care practice. Rather, they intend to (1) clarify the ongoing ethical debates in the context of palliative care, (2) broaden the debates with the help of philosophical and theological theory and (3) propose moral perspectives that allow new orientations for action to emerge.

Chapter 7 thus deals with the question how a hospice in which euthanasia is not provided deals with its patients' requests for euthanasia in the context of a country which officially tolerates euthanasia to be carried out. It results from a participant observation study in one of the hospices in the Netherlands. With the help of four case reports, options in palliative care to deal with euthanasia requests are scrutinised. Sometimes, terminal sedation may be a good alternative for euthanasia, from the patient's perspective as well as from the perspective of the caregivers. The option of withdrawal of life prolonging treatment may give patients a sense of security that their dying process will not be endless. Only in very few, extremely tragic cases, euthanasia may be unpreventable. This chapter makes clear that sometimes, medical decisions that can be defended with the

help of the doctrine of double effect, cause intense emotions on the side of the caregivers. Everyday practice appears to be different from ethical logic.

Chapter 8 analyses the issue of terminal sedation in palliative care practice. While euthanasia is by far the most debated topic in the Netherlands, the issue of terminal sedation has up to now not been given the attention it deserves. It is argued that terminal sedation is not the same as euthanasia from a moral perspective. If we assume that the taking of another person's life is at least *prima facie* wrong, and if we assume that intentions are relevant for the morality of our actions, terminal sedation is a morally better option than euthanasia. However, some patients may not want to die unconsciously. Some may persist in their euthanasia request. These are hard cases in which it is problematic to give final answers. But others may prefer sedation to euthanasia, for instance because they do not want the team that has cared for them to actively end their lives. That is why it is imperative to provide patients who want to die with at least an alternative. Patients requesting for euthanasia should be given a choice. If that is so, the issue of terminal sedation deserves more attention in the Dutch debates on euthanasia than it has received so far.

The last chapter deals with the question to what extent clinical trials can be part of palliative care. Certainly, patients who are about to die should not engage in such trials. But for patients for whom the time of death is still relatively far ahead, clinical trials may be an option. Clinical trials do not serve the well-being of the patient. What's more, they can cause serious harms. In other words, they put that at risk what is at the heart of palliative care. Again the notions of authenticity and hope are proposed to provide a way out of this tragic dilemma. Some patients' lives may gain meaning by engaging in clinical trials, not as a last possibility to cling to cure but as a means to help the treatment of future patients improve.

The conclusion of this thesis focuses on four challenges that lie ahead for palliative care in the nearby future. In this study, directions have been proposed to meet these challenges but further research is necessary. First, further research is required to demarcate palliative care from other medical practices. The specificity of palliative care is for an important part a moral specificity and its articulation is primarily an ethical enterprise. Second, if new enriching perspectives on palliative care are to emerge, historical, philosophical and theological analyses of moral notions used in the debates need further development. Third, debates on medical decision-making at the end of life need to be broadened, stressing alternative palliative modalities for euthanasia and assessing what patients really mean when they say that they want to die. Fourth, increasing interest in palliative care has stimulated the development of new

attitudes towards our mortality in which it is acknowledged that it is our mortality that enables us to give and receive meaning in life. These new attitudes towards death and dying need further attention.

CHAPTER 1

ETHICAL THEORY AND CARE PRACTICE

A THEOLOGICAL PERSPECTIVE

A slightly modified version of this chapter was published as*:
Janssens MJPA, ten Have HAMJ, Medische ethiek en zorgpraktijk. Een diagnose vanuit moraaltheologisch perspectief. *Tijdschrift vcor Theologie* 1999; 39: 162-177.

ETHICAL THEORY AND CARE PRACTICE

A THEOLOGICAL PERSPECTIVE

Introduction

"Academic theology seems to have lost its voice, its ability to command attention as a distinctive contributor to public discourse in our culture ... To gain hearing in our culture, theology has often assumed a voice not of its own and found itself repeating the bromides of secular intellectuals in transparently figurative speech. Theologians with something distinctive to say are apt to be talking to themselves ... Can a theologian speak faithfully for a religious tradition, articulating its ethical and political implications, without withdrawing to the margins of public discourse, essentially unheard?" (Stout, 1988, p. 163). According to Stout, modern academic theology seems to be in a position that can be called tragic. If it understands itself as theology, it will have to withdraw from public discourse. If it wants to participate in public discourse, it will have to refrain from its distinctive theological preconceptions. For moral theology both options are unsatisfactory. Moral theology should be situated on the intersection of church and society. It wants to be 'proper theology' and at the same time it wants to be of public interest (Merks, 1995).

It can be argued that the concern for the relative absence of theology in public discourse is not entirely justified. If one considers the Dutch media, one will have to acknowledge that the voice of theology is not absent at all. Theology does have a distinctive voice in various public debates. Debates on the 24-hour-economy received much input from theologians. In debates on the status of asylum seekers, theology was not absent at all. Furthermore, one has to acknowledge that in the third world countries, liberation theology continues to be at the focus of interest. And has not feminist theology proved important in the women's movement? On second thought, speaking of 'the' public debate appears to be a simplification; and the statement that theology has lost its voice in 'the' public debate is a simplification too.

However, at least within one realm of the pluriform Dutch society, theology seems to be remarkably absent. This is the realm of medicine and medical ethics. Whereas theology manages to hold up its distinctive voice in various public debates, it seems as if it has lost this voice in the debates on euthanasia, abortion, genetics, etcetera. In this realm theology does seem to have withdrawn to the margins of public discourse.

In this chapter, the marginalisation of theology within the realm of medical ethics will be scrutinised. First, it will be argued that this marginalisation can be explained by the self-understanding of current medical ethics. It is claimed that modern medical ethics has subordinated itself to medicine. It has adopted a medico-technical theoretical framework within which technical problems require technical solutions. Modern medical ethics has lost its critical distance towards medical practice. This loss can explain why modern medical ethics has separated itself from fundamental theological (and philosophical) theory. Because medical ethics is in lack of critical distance towards medical practice, important perspectives have systematically fallen outside its scope.

In the second paragraph, it will be argued that a reinsertion of these perspectives requires a reorientation of medical ethics towards more fundamental philosophical and theological theories. It will become clear that medical ethics should eventually not intend to solve problems, but instead should intend to critically scrutinise the discourse of public debates on moral issues and to reveal the particularity of this discourse. The relation between medical ethics and practice is thus not a direct, immediate relation. A direct relation to medical practice is reserved to the actors in the field, for instance physicians and nurses. Instead, the relationship between medical ethics and medical practice is mediated by that which has already been said by others. The paradox is that medical ethics will regain its practical relevancy if it will resume a critical distance to medical practice.

If medical ethics understands itself in this new way, an orientation towards theology and philosophy is required. In the third paragraph, suggestions for a theologically based medical ethics (or a medical moral theology) will be proposed. The distinction between moral theology and moral philosophy does not relate to their material objects; both can be directed towards a variety of practices. Neither is the distinction located in the formal object; the methodological tools used to approach the material objects do not necessarily differ. Instead, the distinction between moral theology and moral philosophy is explained by the specific interest of the moral theologian, namely relating (Christian) faith to contemporary practices in the conviction that the Christian tradition is of relevance for these practices.

Theological medical ethics does not start from a vacuum. In formulating and analysing new theoretical approaches towards medical practices it has to connect to theories and debates that have already been developed. In the last two paragraphs, two examples will be discussed of debates and theories to which a theologically based medical ethics can connect in order to formulate innovative

approaches towards medical practice and thus be practically relevant. The fourth paragraph discusses the past, and to some extent forgotten, debate on what used to be called anthropological medicine. In the fifth paragraph the current debate on palliative care will be addressed. Both debates reflect(ed) an increase in attention towards specific care practices. This shift in attention does not only require an adaptation of medicine. It also reveals the necessity of a reorientation of medical ethics itself.

1. The technological framework of medical ethics

The marginalisation of the role of theology in medicine can be explained by the assimilation of current medical ethics to a medico-technical framework. Also the anthropological assumptions of medicine do not differ from the anthropological assumptions which medical ethics has adopted as its own.

The domination of a medico-technical theoretical framework in medical ethics has been analysed by Zwart (Zwart 1993; Zwart 1995). Zwart argues that we have to return to the historical beginning of medical ethics in the Netherlands. He locates this point of departure in Van den Berg's *Medische macht en medische ethiek* (medical power and medical ethics), published in 1969 (Van den Berg, 1969). In this book, Van den Berg formulates a contrast experience at the bedside of a blind and severely handicapped child with the words "*Het is niet juist*" ("it is not right"). This experience convinced Van den Berg that not everything which can be carried out should be carried out. Acknowledging this experience of concern in regard to the recently developed technological possibilities of medicine, the task of medical ethics is said to limit medical power by creating room for patients' self-determination. The new medicine was in need of a new medical ethics. The old maxim of medical ethics used to be to preserve human life where and whenever possible. The new maxim of medical ethics should, according to Van den Berg, be to preserve human life where and whenever meaningful. The application of this maxim to concrete cases became central for the self-understanding of the new medical ethics. Zwart writes: "The new medical ethics thus started to answer the questions posed by medicine in technical terms. Technical problems require technical answers" (Zwart, 1995, p. 31). At the moment Van den Berg formulated his new moral dictum, the initial contrast experience had already subsided. In Van den Berg's formulation of the maxim, the new discourse of medical ethics is already present. The new medical ethics has positioned itself within a technical framework.

It is possible to argue that medical ethics has become more multifaceted during the last thirty years. Indeed, the application of the above-mentioned maxim is no longer considered to be the only task of medical ethics. Towards the end of the 1970s four moral principles were formulated in the U.S. (sometimes ironically called the 'Georgetown Mantra'): respect for autonomy, nonmaleficence, beneficence and justice. These principles served partly as tools for medical ethics in answering questions with regard to the application of the maxim. This principlist ethics has received much criticism. But it can still be argued that a significant part of current medical ethics continues to be guided by a medico-technical framework aimed at problem solving through application of ethical principles. This observation can be underlined by discussing contemporary representatives.

"Problem solving in applied ethics" is the subtitle of a doctoral thesis of Van Willigenburg (Van Willigenburg, 1991). It is a study of the structures and dynamics of the reasoning process through which an ethical expert reaches a moral conclusion with regard to a concrete moral problem. According to Van Willigenburg, the ethicist has "expertise ... in quick problem solving" (Van Willigenburg, 1991, p. 15). He is familiar with moral notions and argumentations and is therefore better equipped to provide quick and sound advice in moral deliberations than other participants. From a methodological point of view, the ethicist should be strictly rational and completely explicit. That explains the last sentence of the thesis: "The enlightenment-spirit of Bentham's work should be possessed by anyone who claims to be an expert advisor in the field of ethics" (Van Willigenburg, 1991, p. 221). The ethicist may be an expert in moral reasoning, he should however not assume the role of a prophet. Van Willigenburg considers him a guest of medicine and therefore he should be modest towards his hosts. Ethicists are advisors in service of medicine. Questions with regard to the values and goals of medicine as such lie beyond the reach of ethics. If, for example, ethicists argue that medical ethics is often (mis)used in order to legitimise technological progress (Ten Have and Kimsma, 1987), they are called for caution by Van Willigenburg: "... the question is whether the ethicist will be able to carry out fruitfully these research tasks. Serious mistakes may be made" (Van Willigenburg, 1991, p. 38).

In the ethical discourse of which Van Willigenburg is a representative, medical ethics is regarded service to medical practice. Moral problems that occur in medical practice have to be solved by the ethical expert. Medical practice prescribes the *logos* of ethics. Medical practice itself cannot be subject to critical analysis because of a pragmatic reason and a theoretical reason. The pragmatic reason instructs the ethicist not to offend his host. Theoretically, it can

be argued that if medical practice is to formulate the ethicist's tasks, a critical distance to medical practice is no longer possible. The ethicist becomes captivated in a foreign discourse that initially was not his/her own. Medical ethics has lost its proper framework and when Van Willigenburg uses the metaphor of guest and host he seems conscious of this very loss. After all, as a guest you have to adjust to your host, whether you like it or not. The self-understanding of medical ethics as a guest of medicine can be further clarified by analysing the anthropology of medical ethics.

As long as Cartesian dualism continues to be the underlying paradigm of medical practice (Crul, 1999), it is part of the underlying assumptions of current medical ethics as well. In medicine, the human being is approached as a duality of mind and body. Given the self-understanding of medical ethics as outlined above, it is not considered the task of the ethicist to criticise this anthropology. The body is object of the autonomous will of the person. It is an instrument, used to promote the self-fulfilment of the person. As long as the person does not give his consent, nobody is allowed to touch his or her body. Dupuis and Thung explain: "... corporeality is defined as a boundary, namely as the realm to which values, norms and choices do not apply. Human behaviour, in the sense of choice-making, only starts beyond this border of corporeality..." (Dupuis and Thung, 1988, p. 71). While medicine is interested in the body, medical ethics is interested in the autonomous person who is the owner of the body. Ethics determines the conditions under which medicine may touch and invade the body. Therefore, the paradigm of medicine and medical ethics is the same. If the person consents, medicine is allowed to intervene. The question whether the intervention is morally allowed has thus become dependent on the right to self-determination of the person. The intervention as such is no longer scrutinised. After all, that would imply a critique of the values and goals of medicine and that is beyond the proper scope of ethics.

This discourse fails when medicine's interventions are no longer successful; when cure of the defect body appears no longer possible. The paradigm which considers the body as instrumental for the person's self-fulfilment, belongs exclusively to the realm of curative medicine. The instrumental notion of the body also presumes the social independence of the person. When personal development is frustrated due to a bodily defect, medicine is there to remove the defect as quickly and effectively as possible. When however, the body has become chronically ill, the discourse of medical ethics does no longer suffice. Medical ethics has difficulties in coming to terms with care practices such as nursing home medicine or care for the elderly (Pijnenburg, 1992). It has been argued before that the increasing number of

chronic patients has demonstrated the urgency of an adjustment of medicine (Sporken, 1983). Now, it can be added that an increasing need for care practices also reveals the urgency of an adjustment of medical ethics.

If this diagnosis of current medical ethics is correct, medical ethics can be characterised as an ideology. According to Boff, an ideology is "A theory that is developed in an immediate relation with lived life and the practical functions of empirical existence. Because this theory has almost no critical distance towards concrete life, it digests matters from their utter, perceivable form of appearance ... Ideology thus refers to a disguised theory, a false consciousness" (Boff, 1983, p. 92).

2. The proper context lost

Many ethicists involved in medical ethics are affiliated with a medical faculty and university hospital. The link to medical practice is constituted through ethical consultancy, moral deliberation, memberships of the ethical committees, or preparation and evaluation of protocols. Many ethicists do participant observation studies in clinical wards to find out how the actors in the field deal with moral issues in everyday practice (Ten Have and Lelie, 1999). Without this link to medical practice, medical ethics would not exist. But at the same time, the dynamics between ethical theory and medical practice should be subject to continuous scrutiny in medical ethics. Medical ethics should continuously reflect on its own theoretical foundations in order not to become an ideological legitimisation of medical practice. As argued above, a medical ethics which understands itself as a service to medicine shows characteristics of an ideology. Important perspectives fall out of its scope due to a lack of critical distance. In this paragraph, it will be argued that a re-orientation towards the theological and philosophical underpinnings of medical ethics is necessary in order to (1) keep a critical distance and (2) be practically relevant. The flaw of current medical ethics has everything to do with the little use of philosophical and theological theories.

2.1. Critical distance

The relationship between medical practice and medical ethics is a mediated relationship. Ethicists are never subjects of medical decisions and actions and are not supposed to take over the role and duties of the caregiving team. Moral responsibility for decisions remains with the team. The subject matter of the

ethicist is always of a second order. In other words, the subject matter of medical ethics consists of what has already been articulated by others (Zwart, 1998). Ethicists should scrutinise this material in a creative way. If the debates have already been formulated in moral terms, these terms should be scrutinised by making use of theological or philosophical expertise. Which terms have been used in the debate? What do these terms mean in the debates? Which meanings are implicitly or explicitly attributed to them? And, especially, which moral meanings remain unspoken? Which terms are not used? Such kind of questions intend to reveal issues that may seem self-evident in the debates but are on second thought less self-evident than initially believed. In other words, they bring the particularity of the debates to the surface and in doing so, they reveal much about our contemporary self-understanding. The current medical ethical debates, together with the prevailing moral notions, are confronted with other, forgotten debates. Notions can be re-introduced that may have disappeared from the common theoretical frameworks and paradigms. Meanings attributed to moral notions in specific debates can be confronted with different meanings they used to have in earlier times but which have not survived. Notions that are central in debates outside the realm of medical ethics can be confronted with medical ethical debates. In this way, perspectives can be revealed that remained hidden before. The ethicist's task is a Socratic task: seeming self-evidences are revealed and put under renewed critique.

As long as medical ethics continues to perceive itself as service to the medical profession, it is hardly able to escape from the used paradigms and conceptual frameworks, as well as the established consensus. However, medical ethics should not take for granted the regular discourse or the legitimacy of consensus. Then, it may appear that consensus have been established in a particular domain *because* important moral meanings are (1) left unconsidered or (2) are referred to the private realm in which individuals are said to be free to follow their preferences. These moral meanings, which cannot be reconciled with the consensus, must be re-introduced in the medical ethical discourse. Medical ethics is revelation of forgotten moral meanings.

Ethics always starts from certain suppositions. The ethicist has particular interests. And honesty requires that these interests are made explicit. Hauerwas has rightly pointed out that ethics is always in need of an adjective, a 'qualifier' (e.g. liberal, Christian or pragmatic) (Hauerwas, 1983). Ethics can never pretend to be neutral but is instead based on certain moral convictions that prevail in well-defined communities. The (often implicit) pretension of current medical ethics to make use of a 'neutral moral language' can be exposed as an ideology as defined by Boff. The adjective 'neutral' should be replaced by another

adjective that denotes the particularistic character of the ethicist's suppositions (Welie, 1998).

Therefore, also the conception of medical ethics proposed here is in need of a qualifier. A Socratic ethic, questioning consensus, is always an ethic that is based on certain interests. Thus, only some meanings are revealed, other, perhaps equally important meanings, remain hidden. This process (that can be considered an eclectic process) can be explained by the necessary preconceptions of the ethicist. We are now in the middle of what has been called the 'hermeneutical circle': meanings alter preconceptions but cannot exist without preconception. This means that ethics can never be definite, can never speak final words, and is always characterised by ambiguity.

2.2. Practical relevance

Practical relevance of medical ethics has not so much to do with solving problems. Solutions to problems are a responsibility of the actors in the field. As Van Tongeren has stated, the goal of ethics is a sensitisation of moral experience (Van Tongeren, 1988). In revealing lost moral meanings, current debates can be broadened. Practices that seemed unproblematic before can become problematic again and are thus put at risk. New meanings require a revision of the central notions in the debates. Sometimes, prevailing moral notions are re-interpreted. Sometimes, they are in need of replacement by other notions that are better equipped to identify the problematic issues at stake. If common language is inadequate to formulate what is at hand, neologisms can be introduced (Zwart, 1998). In revealing moral meanings, the actors in the field (the caregiving team) become sensitised in dealing with moral problems that occur in everyday practice. This may mean that, instead of making it easier, ethics can make it harder to solve problems or provide concrete directions for decision-making. Problems may appear unsolvable, situations may appear tragic, exactly because the meanings that are brought to the surface appear to have an inevitable moral validity.

The ethics that is proposed here acknowledges its particularity but does not lose its normativity. The introduction of meanings and the critique on the current debates does open room for alternatives in dealing with practical problems. New orientations for acting can be suggested.

3. Towards a medical moral theology

Medical ethics usually locates theology in the sphere of intra-ecclesiastical debates; only there exists a consensus on theology's preconceptions (Kuitert, 1988). Again, current medical ethics presumes a neutrality on the side of the ethicist. That ethics is always interpretative, starts with suppositions and is always in need of an adjective, is not acknowledged. Therefore, not only theological ethics, but also philosophical ethics is located in spheres that lie outside medical ethics. Medical ethics nowadays exists because of an *Entmachtung der Überlieferung*, a disempowerment of tradition (Gadamer, 1975). But moral theology is explicitly based on the acknowledgement of the authority of tradition(s).

Traditionally, moral theology has been based on two norms: the bible (*norma non normata*) and the tradition (*norma normata*). A third norm should be added: experience. After all, the truth of the bible and the Christian tradition does not exist without the acknowledgement that it has practical meaning for humanity. Whereas philosophical ethics can be defined as hermeneutics of experience (Van Tongeren, 1988), moral theology can be defined as hermeneutics of experience in the light of bible and tradition. The material object of moral theology does not differ from the material object of moral philosophy. And if, as outlined above, the goal of (medical) ethics is the sensitisation of moral experience, this goes for moral philosophy as well as moral theology. The formal object of moral theology does not differ either from the formal object of moral philosophy. The methodology of moral theology needs a philosophical underpinning. Moral philosophy is of relevance to moral theology in the sense that moral theology always presupposes a theologically relevant moral philosophy (Mieth, 1996).

This does not mean that moral theology would not have a distinctive significance as a separate discipline. In the biblical and Christian tradition, people have expressed their experiences which continue to carry significance in our times. It is an ecclesiastical duty to keep those experiences alive. Moral theologians have to interpret and actualise these experiences in the variety of current debates and practices. They assume that many of these experiences, not all, are still relevant and able to reveal important moral meanings, also in the context of a secularised, post-modern society. The preconceptions of moral theology are basically rooted in the lived Christian tradition. The Christian tradition however, is not a crystal clear concept. People have murdered and tortured, and apart from these crimes, a lot more harms have been committed in the name of the Christian tradition. Moreover, the Cartesian dualistic

anthropology, criticised above, can draw on important parts of Christian theology. Therefore, simply acknowledging the normativity of the Christian tradition is problematic. If it is said that the Christian tradition carries normativity, it always has to be seen in the context of our contemporary subjectivity. Theology must be situated at the crossroads of our contemporary experience and the truth of the Christian tradition. Truth does not exist without experience. At the same time, truth always carries objectivity because it is not completely dependent on our interpretation.

Moral theology is concerned with the church and intra-ecclesiastical debates. But moral theology is also concerned with society in general (Demmer, 1987; 1989). In the latter context, also non-Christians are addressed. It is also this larger societal context that is of special concern in the context of this chapter.

It has already been argued that the tasks of moral theology and moral philosophy are the same, namely the articulation and explication of moral meanings. The difference between the two disciplines relates to their preconceptions. Only in the light of these preconceptions, it is understandable where the discomfort with current debates comes from and which meanings are actually formulated and scrutinised. Moral philosophy needs an adjective qualifier as well as moral theology. But for moral philosophers this preconception is not fixed. A liberal moral philosopher will reveal other meanings than a Christian philosopher.

For moral theology, certain options are excluded. If one accepts the norm of the bible and tradition, not everything is possible. For current medical ethics this is where the weakness of theology lies. But it can also be seen as her force. It is the connection with the Christian tradition which provides the moral theologian with the critical potential in the face of practices which reduce humanity.

In the introduction it was pointed out that the anthropology of medicine, together with the anthropology of current medical ethics, is a reduced type of anthropology. Below, an alternative anthropology will be briefly outlined which is relevant for medical ethics and which articulates insights from the Christian-theological tradition.

According to this tradition, everything is created by God and is aimed at returning to God: 'exitus' is followed by 'reditus'. Since God is the creator, the whole of His creation contains traces ('vestigia') of His that refer back to Him. However, man is attributed a verisimilitude with God. Man is not only considered to be a trace but also an image of his/her Creator. For a long time,

this 'imago Dei-character' of man was situated in the rational part of the soul; it was thus considered separate from the passions and the body. It can be argued that this view is comparable, at least in its dualism, to the currently dominant view of medicine and medical ethics. However, especially Thomas Aquinas has modified this 'Neo-Platonist' view as he pointed out that man should always, first and foremost, be considered as oneness of soul and body. The soul, conceived of as the form of the body (*forma corporis*), becomes detached from its original state at the moment of death, when the soul is separated from the body (Thomas Aquinas, 1996). Full beatitude is not possible without the body (see also De Grijs, 1967).

The scheme of *exitus – reditus*, although originally part of a Neo-Platonist framework, provides the image of God-character of man with a dynamic strength. In order to return to God, man is given the liberty to choose. This liberty is considered by the church as a token of man's nature (as image of God) (Gaudium et Spes, 1967). The moral life of man thus becomes situated in a dynamic framework; man has been created by God, lives in the hope of returning to God and reach full beatitude at the end of times. Since the resurrection of Christ, God's kingdom has already been established, albeit still in an imperfect state. It is already there, but not yet in its perfect form. Moral life of man is situated in the midst of the 'already' and the 'not-yet'.

Important in this context is that in the Christian tradition, the human person is considered first and foremost as a unity of body and mind. Distinctions between mind and body can be made only after having realised the unity of the person. The distinction is not said to be between the body and the person. Instead, the human person is said to consist of mind and body which are mutually dependent. As the person is considered an image of God, and therefore in a more privileged situation than all other creatures, he or she has been given dignity. Human dignity is an ontological category which everyone, as a person, has. At the same time, dignity can also be considered a moral criterion. Acknowledging dignity and protecting it in situations in which it is threatened is therefore the criterion for a moral life. In protecting dignity, human beings can anticipate the fulfilment of the Kingdom of God.

Debates on potential attributes that would determine the personhood of human beings do not have a place in theology. Human beings simply *are* persons, personhood is an ontological category, independent of the concrete state human beings can be in or the particular characteristics they have. If we also recognise that at least some philosophers argue that it is impossible to identify the attributes that are essential for personhood, it seems irrelevant for theology to discuss these attributes (Gordijn, 1996).

4. Theological medical ethics and anthropological medicine

In formulating new, practically relevant perspectives on medicine, theological medical ethics can draw on earlier debates which did give rise to new orientations, but have been marginalised by current medical ethics. In recapturing and reviving outcomes of such debates, theological (or philosophical) medical ethics can reveal important, but forgotten, meanings in current debates. An example is the recent history of anthropological medicine.

Anthropological medicine is a reaction to a kind of medicine, dominant in the first half of the 20th century, which was almost exclusively oriented towards the sciences. Anthropological medicine is a generic term; it covers various meanings. However, three basic characteristics can be distinguished (Ten Have, 1995). First, anthropological medicine rejects any form of dualism. The patient is considered as a unity of mind and body and can therefore not be reduced to his illness. Second, anthropological medicine criticises the uncritical faith of medicine in the sciences. Anthropological medicine considers medicine to be first and foremost an art, in which there is no place for strictly objective knowledge. Third, anthropological medicine does not only understand illness as a negative entity. It is argued that we should also attribute a positive meaning to illness. "Illness is a way of being a person … illness has to do with an answer of the person to his or her existence" (Ten Have, 1995, p. 11). With the rise of modern medical ethics at the end of the sixties, the orientations provided by the anthropological medicine faded into the background. Questions with regard to the goals and values of medicine came to fall outside the scope of medical ethics. The new moral discourse adapted to the paradigm of curative medicine with its almost exclusive orientation towards physical health.

Within the Christian tradition however, physical health has never been an absolute value. Health (perhaps it is more accurate to speak of 'wholeness') does not only represent the physical function of a person, but refers also to psychological, social and spiritual aspects. In this sense, health is never fully present. To a certain extent, infirmity inevitably belongs to human existence. Physical health is only one aspect of human existence, albeit an important one, that makes a life in dignity possible. And curative medicine is only one societal realm through which people are helped to develop and fulfil themselves. Other societal realms can be equally important, or even more important. The task of medicine is not so much to fulfil people's preferences. More important is to enable people in the context of a society to live a life in dignity, with or without physical limitations (Government Committee on Choices in Health Care, 1992). Medicine, in this sense, is truly service to mankind, a conception that was also

formulated by Pope John Paul II addressing the medical profession: "No one of you can limit yourself to being a doctor of an organ or apparatus, but you must treat the whole person, and what is more, the interpersonal relationships which contribute to his well-being" (Pope John Paul II, 1993, p. 191).

For anthropological medicine, it is not only the individual person who is central. Also his dialogical relationships, which essentially contribute to the person one is, are crucial. Schotsmans has added a third level, apart from the levels of the 'I' and the 'I and you', namely the level of 'we'. With this level, he is referring to the solidary sense of responsibility of people in the context of a society (Schotsmans, 1994). This broader perspective on personhood can be applied to a variety of problem areas.

In 1998 for example, there was a lively debate on the implementation of legal requirements for organ donations in the Netherlands. Earlier that year, all citizens received a registration form asking whether they would want to donate their organs after death, or leave the decision to their (bereaved) loved ones. According to the law, everyone who has returned a written declaration of consent for the donation of their organs, the organs can be removed after the moment of death. However, in practice, proxy consent is always requested, even if a written consent form has been returned by the deceased. If the loved ones of the deceased refuse the removal of organs, the organs will not be removed.

Whereas the government, appealing to the level of the 'we', stimulates people to give their written consent and puts the level of the 'I' central in its justification of the removal of organs, in the end, the second level of the 'I and you' decides, even if the decision of the bereaved goes directly against the wish of the deceased. Whereas the law permits the removal of organs in such cases, practice appears to be more ambiguous. And probably, this practice is not only signifying respect for the wishes of the bereaved but also reflects an understanding that dialogical relationships are essential for the person of the deceased himself. Current medical ethics might object to this practice, appealing to the first level of the 'I' and the autonomy of the individual. But on second thoughts, it remains to be seen whether the deceased is actually ignored.

Another question is whether a person who refuses organ donation does have a right to receive another person's organs. This question can be answered with the help of the notion of 'solidary responsibility' as a part of the perspective on personhood that was outlined above. Moreover, if one argues that life in solidarity with and responsibility for others is a part of personhood, the question does not even arise. Self-evidently, this person should be allowed to receive other persons' organs.

5. Theological medical ethics and palliative care

In 1983, Sporken argued that the increasing number of chronic patients demonstrate the urgency of a modification of the biomedical paradigm. Chronic patients confront medicine with its inability to take away illness. According to Sporken, medicine should shift its attention from curative interventions to care. One of the care practices now very much in the focus of attention is palliative care. Palliative care is defined in the Netherlands as "the continuous, active, integral care for patients and loved ones, by an interdisciplinary team starting from the moment that, from a medical point of view, cure can no longer be expected" (Working group on palliative care, 1996, unpublished).

It is in this context important to realise that palliative care was developed outside the realm of modern medicine, in the independent hospice. The relative distance of palliative care from the formal health care system in these early days provided the opportunity to reveal the blind spots of medicine. Exactly because palliative care was originally organised outside the formal health care system, the relative absence of care in medicine could be brought to the surface. At the same time, from the early start, there was always a consciousness that palliative care was to move back into medicine. Cicely Saunders stated: "... we had to move out, so that attitudes and knowledge could move back in" (Saunders, 1981, p. 4).

Palliative care is called "total care": the medical, emotional, social and spiritual needs and wishes of the patient, together with his/her loved ones are central. From a personalist point of view, it can be argued that palliative care entails a surplus value because the variety of human needs and wishes are acknowledged (Schotsmans, 1995).

Only since the beginning of the 1990s, palliative care has become a policy issue in the Netherlands. This increase of interest is important, not only for patients receiving palliative care but also for the whole of medicine. The development of palliative care has stimulated attention for care practices in general. Palliative care has disclosed the marginalisation of care practices in the context of medicine and in the context of medical ethics. Because medicine was not self-critical, and because medical ethics has lacked critical distance to medicine, it was taken for granted that cure was the exclusive goal of medicine. In other words, because questions with regard to the goals and values of medicine were not addressed, care fell outside the scope of medicine and medical ethics. Because of the growing interest in palliative care, questions with regard to the goals and values of medicine have now returned in public debate.

Palliative care thus not only implies a critique of an exclusively curatively oriented medicine, it also implies a critique of current medical ethics.

From a historical point of view, palliative care was also developed as a reaction against the British Voluntary Euthanasia Society which flourished in this period (see chapter 2). According to Cicely Saunders, pleas for a legalisation of euthanasia could partly be explained because of medicine's drive to prolong patients' lives at all costs with the technological means available. In many cases, the question whether life prolongation contributed to the quality of patients' lives was not posed. The "therapeutic furor" of medicine at that time often did more harm than good. Just as Van den Berg pointed out in the Netherlands, Cicely Saunders was one of the first physicians in the UK to point out that the technological imperative, urging to prolong life where and whenever possible, led to an increase in euthanasia requests. Saunders found herself at exactly the same turning point as Van den Berg. Van den Berg pleaded for patient autonomy and saw no objections to active euthanasia. Saunders' response however, was different as she argued that euthanasia requests can and should be prevented through good palliative care. But both were in the same situation and both agreed that uncritical acceptance of the technological imperative could be harmful instead of beneficial.

Preventing euthanasia requests (and acts) is also one of the reasons why palliative care has received much interest in the Netherlands lately (see chapter 7). However, it is clear that the debate in the Netherlands is increasingly dominated by calculations, procedures and percentages. Depending on the interpretation of the available statistics, one will either favour or criticise Dutch policy. The 'proceduralisation' of the Dutch debate seems to imply that euthanasia would be a morally acceptable act as long as the official conditions are met and the act is carried out in a careful manner. Questions with regard to the morality of euthanasia as such have been marginalised, not only because a vast majority of the Dutch medical profession and the Dutch population in general favour euthanasia under conditions, but also because the medical ethical discourse has exclusively asserted patient autonomy.

Because of the recent development of palliative care, changes are now taking place in the Dutch debate. Questions whether good palliative care can in many cases prevent euthanasia requests are re-issued. Consequently, the morality of euthanasia as such is becoming an issue again. Many people agree that palliative care is not able to take away all euthanasia requests. But if one accepts that in some, maybe many, cases palliative care is able to prevent euthanasia to be carried out, it is necessary to further develop palliative care.

The primary goal of palliative care however, is not to prevent euthanasia requests; the primary goal is to provide good care (Janssens et al, 1999).

In short, the recent shift in attention from cure to care practices requires a conception of medical ethics different from the dominant conception. Medical ethics should reorient itself to its fundamental theological and philosophical roots and initiate debates on the fundamental goals and values of medicine. Care practices, like palliative care, have demonstrated the marginalisation of the chronically and incurably ill within medicine and medical ethics. Moral philosophers and moral theologians should do justice to the discomfort experienced by so many with regard to medical ethics' implicit and exclusive adherence to the traditional biomedical paradigm; they should suggest new orientations and new perspectives.

Conclusion

In the early pages of this chapter, it is argued that theology has not lost its distinctive voice in a variety of public debates but that the theological voice in the medical ethical debates is strikingly absent. It is explained that this absence is due to the current medical ethical discourse which, on theoretical and pragmatic grounds, has insufficient critical distance to medicine. Due to the self-understanding of medical ethics, moral theology has become marginalised: the distinctive theological voice is located in the intra-ecclesiastical discourse where there is a consensus on the fundamental preconceptions. Central to my argumentation is that, because the philosophical and theological perspectives have been relocated outside the scope of medical ethics, important moral meanings have remained hidden. It is the task of medical ethics as proposed here to re-introduce these forgotten moral meanings in the debates so that new perspectives emerge and a sensitisation of the moral experience of caregivers becomes possible.

In reviving relevant moral meanings, moral theology can connect to a variety of earlier or recent debates. This has been clarified with the help of two examples: the debate around anthropological medicine, which has become marginalised by the dominant conception of medical ethics, and the recent debate on palliative care. Especially the latter debate indicates a recent shift of attention, from a dominant interest in curative medical practices to a new interest in care practices. The recent debate on palliative care has created room for a new debate on the values and goals of medicine. It highlights the urgent need for a modification of the biomedical paradigm, not only from the side of

medicine but also from the side of medical ethics. More fundamental questions on medicine require a more fundamental, theologically or philosophically based medical ethics. The paradox is that in recapturing a critical distance towards medical practice, medical ethics will become more practically relevant. In the following chapters, the philosophically and theologically based medical ethics as advocated above will be used to explore the meanings of the concept of palliative care and to analyse and evaluate the ethical debates in palliative care. The practice of palliative care can be helpful in developing a conception of medical ethics that is different from the dominant one. And the theory of medical ethics as outlined above can be helpful in providing new, provocative, and challenging perspectives on the practice of palliative care that can sensitise the experiences, not only of the caregivers in palliative care, but also of caregivers in medicine in general. The relationship between care practice and ethical theory is thus a circular relationship. Care practice stimulates the development of new theoretical perspectives and ethical theory stimulates a broader understanding of care practice.

Note

* Differences with the published version:

- Some information on the history of palliative care, which will be described in other chapters, has been deleted in paragraph 5, in order to avoid repetition.
- The conclusion has been summarised.

CHAPTER 2

ETHICAL AND CONCEPTUAL ASPECTS

OF PALLIATIVE CARE

This chapter has been published as:
Janssens MJPA, Quartier T, Ethische und konzeptuelle Aspekte der Palliativmedizin. *Zeitschrift für medizinische Ethik* 2000; 46: 273-287.

ETHICAL AND CONCEPTUAL ASPECTS

OF PALLIATIVE CARE

Introduction

In almost all European countries an integration process of palliative care with the formal health care system is taking place. While in many countries palliative care started to develop with the foundation of independent in-patient hospices, it is now increasingly organised in the context of the national formal health care systems. This integration process should be seen as a source of many important questions. As long as palliative care was organised in independent hospices, which understood themselves as a separate movement with univocal, often religiously inspired, moral norms and values, the concept of palliative care was also rather clear and homogeneous. However, since palliative care is now increasingly organised and formed in hospital wards, nursing homes and home care services, the concept of palliative care has become ambiguous. In this chapter, it will be argued that in the context of recent developments, the concept of palliative care is in need of a critical analysis. A distinction will be made between normative and empirical dimensions of palliative care.

1. Normative dimensions of palliative care

Palliative care has been defined by the World Health Organisation as follows: "Palliative care is the active total care of patients whose disease is not responsive to curative treatment. Control of pain, of other symptoms, and of psychological, social and spiritual problems is paramount. The goal of palliative care is achievement of the best possible quality of life for patients and their families" (World Health Organisation, 1990, p. 11). This definition may denote important characteristics of palliative care, it does however not provide an understanding of the concept of palliative care. For a critical comprehension of the normative meaning of palliative care it is imperative to make an 'historical detour'. A journey back in time can provide insight in the original motivations of palliative care. And insight in these motivations is in its turn conditional for an articulation of the moral significance of current palliative care.

1.1. History of palliative care

Palliative care has developed from the hospice movement. The origins of palliative care are generally situated in the year 1967, when Cicely Saunders founded the first professional hospice, the St Christopher's hospice in Sydenham, London. However, when Saunders founded St Christopher's, she referred back to organisational forms which originated at the beginning of the Christian era and to hospices which were established at the end of the nineteenth and the beginning of the twentieth century. In her view, the continuity between the modern hospices and the hospices of the early Christian era is larger than the discontinuity: "Although at first we had only sketchy knowledge of hospice history and little conscious connection, today's principles are a modern development of aims comparable to those of the hospices of the early Christian era" (Saunders, 1994a, p. 43). Modern palliative care can and should be understood in the light of these older hospices (Phipps, 1988).

The Latin word *hospes* signifies 'host' as well as 'guest'. From this word originated the word *hospitalis*, signifying 'kindness/friendliness'. *Hospitalis* thus refers to the feeling of the host towards his guests. Another word referring to *hospes* is *hospitium*. The meaning of the word *hospitium* was originally the same as the meaning of *hospitalis* but gradually *hospitium* started to refer to the place where the feelings of 'hospitality' are experienced (Saunders, 1996).

In the fourth century AD, the church in the orient had already established a number of so-called *xenodochia* (Greek for *hospitium*) which intended to give care to pilgrims and other travellers. The caregivers in these houses based their initiatives on the text in the gospel of St. Matthew (25;35): "For I was hungry and you gave me something to eat, I was thirsty and you gave me something to drink, I was a stranger and you invited me in … I was sick and you looked after me … I tell you the truth, whatever you did for one of the least of these brothers of mine, you did for me." It was on the seven works of grace that the *xenodochia* based themselves (Goldin, 1981).

At the end of the fourth century, the *xenodochia* were introduced in the Occident where the term *hospitium* became customary. These *hospitia,* or hospices, were founded along the pilgrimage roads and, like the *xenodochia*, they intended to provide shelter and care for the pilgrims on their way to the holy cities. In the beginnings, these hospices did not have a medical function but gradually medical care for the pilgrims, who were often injured, started to become more important. Many hospices started to be frequented by people who were living in the neighbourhood and were in need of medical care. Thus, medical care became an integral part of hospice care. Like the *xenodochia*, the

hospices derived their inspiration from the bible, especially from the seven works of grace.

These hospices were to flourish until the time of the Reformation when many hospices were dissoluted and only small numbers were reinstated on a secular basis (Clark and Seymour, 1999). The flourishing time of the hospices turned into a time of decay. Beginning from the age of the Enlightenment, new hospitals were founded. Medicine became a positive science and the hospitals proliferated with a strong interest in scientific advancements. Focus was on acute and curable diseases. Chronic illness, terminal illness, and care for the aged were hardly given attention. The poorer parts of the population were also not admitted in the new hospitals. In the middle of the nineteenth century, an important development took place in reaction to the care provided in the hospitals.

The Irish Sisters of Charity, an active religious order led by mother Mary Aikenhead, were in their hospitals in Dublin occupied in the care for the ill, among whom there were also people suffering from chronic and terminal illness (Kerr, 1993). Twenty years after the death of Mary Aikenhead, in the year 1879, their first hospice, specifically designed to meet the needs and wishes of the dying, was founded in Dublin and was named Our Lady's Hospice for the Dying. In this hospice, medical care was provided only to a limited extent. Especially nursing care and spiritual guidance were focused on. Historical research has shown that pain and symptom treatment was primarily considered as a means to obtain the higher goal of spiritual reconciliation or, if necessary, religious conversion of the lapsed patients (Humphreys, 2000).

Because of the charisma of this hospice, the establishment of other hospices in the United Kingdom followed like for example St Joseph's Hospice in London (1905) and St Luke's House for the Dying (1893). These hospices were founded by people from the middle and upper class and were intended to provide care for the 'respectable dying poor'. Dying patients from the poorest part of the population were admitted only in exceptional cases. An important goal of these hospices was to bring the lower class population back in contact with the church as many of them had abandoned the official religious institutions. Thus, a form of social control was to be re-established on a forgotten part of the population (Humphreys, 2000).

Possible criticism on conservative motives behind the foundation of these hospices leaves their positive influence on the later historical development of palliative care untouched. The hospices did for example not correspond at all with the image of a death clinic which had already begun to spread at that time. Hospice care showed that the dying are not only dying. First and foremost, the

hospice caregivers wanted to demonstrate that their patients ought to be seen as living fellow human beings. Reports on the daily life in hospices mention for example numerous jokes on hospice life (Goldin, 1981).

It was in these hospices where Cicely Saunders worked as a professional nurse (Clark, 1998). Later on, she was to learn much on pain and symptom control in these hospices. But medical care was still not considered important. Focus of attention was on nursing and spiritual care. Only in the 1950s, important developments in the area of pain and symptom control started to take place. In this time, the first pain clinics originated, and progress was made in the areas of (palliative) radiotherapy and chemotherapy. Important publications improved the psychosocial care for the dying and their loved ones. In this context, the contributions of Elisabeth Kübler-Ross must be mentioned. Based on many conversations with dying patients, she induced five phases which would characterise the emotional situation of the patients in relation to themselves and their social environment: denial, anger, bargaining, depression and acceptance. In her publications, she stressed the importance of supporting terminally ill people in these emotional situations. Even though according to Kübler-Ross it was right to allow for all of these emotions, eventually, she considered the emotional situation of acceptance a goal of psychosocial care (Kübler-Ross, 1969). Research in bereavement, which was recently carried out, showed that also the 'significant others' of a dying patient are in need of supportive care. Their emotional situations may run parallel to the emotional situations of the patient and it is imperative to create room for their emotions too (Quartier, 1999). Also the studies of P. Ariès on death and dying contributed to a more open awareness of these issues in western society (Ariès, 1974). In the light of the above-mentioned developments, the foundation of St Christopher's hospice in 1967 can be better understood.

Two additional factors require attention. First, there was a fundamental discomfort in the British hospices with regard to mainstream medicine and the care for the dying in the general hospitals. In mainstream medicine, care for the dying was still left unconsidered to a large extent. Physicians experienced the death of their patients as a personal defeat. When curative treatments were ineffective, it was said that nothing could be done anymore for the patient. Only few physicians were interested in the progress that was made in the area of pain and symptom control. Pain and symptom control were medicine's stepchild. Because the available knowledge in these areas was insufficiently adopted, patients were suffering unnecessarily. In most cases, the family was informed of the inevitable death of the patient, but the patient him/herself was not informed of the prognosis. And even though new knowledge was published on

psychosocial and spiritual care for the dying, only little attention was given to these realms of care. Psychological processes of patients and loved ones were hardly addressed. This practice stands in sharp contrast to knowledge of the integrative process of the dying and their significant others as psychological processes can hardly occur and develop.

Secondly, the British hospices have from the beginnings been characterised by a moral discomfort with regard to voices in British society that pleaded for a legalisation of euthanasia (Clark and Seymour, 1999). The British 'Voluntary Euthanasia Society' was founded in 1935 but started to flourish in the context of the medical-technological progress that was made. The increasing membership of this society co-incided with the increasing attention for the young hospice movement. The hospices wanted to show that good medical, psychological, social and spiritual care could take away or prevent requests for euthanasia (Saunders, 1994b). As was shown in chapter 1, the hospice and the euthanasia movement both intended to react to the same problem.

Concludingly, the foundation of the first professional hospices can be clarified in the light of societal developments, together with fundamental discomforts with regard to pleas in favour of legalisation of euthanasia and with regard to the curative, activistic paradigm of mainstream medicine.

An important reason why the British hospices started to proliferate so rapidly, was the charisma of Cicely Saunders. In the year 1973, six years after the opening of St Christopher's, there were already 25 professional in-patient hospices in the UK. The publications of Saunders became well-known in the USA and Canada where the psychosocial care for the dying had already gained interest because of Kübler-Ross' publications. Here, the idea of hospices without beds which were exclusively designed to provide home care (hospice-at-home) originated. In New York, the first teams were founded which were exclusively designed at consultation of physicians and nurses in the hospital. In 1977, the National Hospice Organisation was founded, which currently has a membership of over 1500 institutions. In the year 1975, Dr. Balfour Mount founded the first palliative care unit in Montreal, Canada. In the context of bilingual Quebec, the term 'hospice' was unsuitable because of its specific meaning in the French language (referring to institutions for the destitute). At the opening of this unit, the term 'palliative care' was used for the first time. Almost all caregivers of this palliative care unit had received their education at St Christopher's (Doyle, Hanks and MacDonald, 1996).

1.2. Articulating the moral significance of palliative care

The integration process of palliative care with the formal health care system which, as we shall see below, is currently taking place in almost all West European countries has led to an increasing ambiguity of the concept of palliative care. An oncologist, who meets his patients years before death, is likely to use a broader, wider ranging concept of palliative care than a hospice physician, who meets his patients only weeks before they die. While care given in the context of hospices is mostly limited to the terminal phase, care given in the nursing homes is given over a much longer period of time. Hospital care for patients with a life threatening disease begins from the time of diagnosis (or even before that time). Moreover, in geriatric wards, oncology wards, nursing homes and home care services, the provision of palliative care is only a part of daily practice. The question arises how palliative care can be demarcated from other practices. Is a univoque demarcation possible at all? Apart from the scope and demarcation of palliative care, an increasing dissension can be perceived with regard to the moral norms and values of palliative care. The ethical validity of the values and norms on which there was a consensus in the hospice movement is increasingly subjected to debate. In other words, as palliative care is integrating in the various health care systems, it is also increasingly required to render account of its moral norms and values in the context of the ethical debates. Concludingly, the question for the moral significance of palliative care is an urgent and important question. But how should this moral significance of palliative care be articulated? Which are the main characteristics of palliative care and what does history tell us about these characteristics? First of all, it will be argued that one main characteristic of palliative care relates to the concept of total care. Throughout the history of palliative care, the total needs and wishes of a patient have been the criterion for the care given. Palliative care has always resisted the reduction of a human being to a physical body. Secondly, palliative care cannot be understood without its discomfort with the high-tech, curative health care of the past. The lives of the dying need not always be prolonged by the technological means available. The process of dying should not be denied. Instead, justice should be done to it (Kübler-Ross 1993; Quartier, 1998).

1.2.1. Palliative care as total care

For a long time, the main task of mainstream medicine has been the removal of physical illness. Medicine's dualistic anthropology (see chapter 1) can explain a good deal of this preoccupation. The emotional and spiritual suffering of people

was not considered to lie within the scope of medicine. Patients were seen as bodies, not as human beings with a variety of needs.

This anthropology is contradictory to the anthropology of palliative care. As indicated in chapter 1, palliative care has been characterised by a Christian anthropology throughout its history. Palliative care conceives of man as a unity of physical, emotional, social and spiritual needs and possibilities. The acknowledgement of this variety of needs and possibilities can already be found in the text of St Matthew where the physical, social and emotional needs of people are situated in a spiritual framework. Also in the first hospices for the dying, man was conceived of as a unity of body, mind and soul even though eventually 'soul care' was considered the most important form of care (Humphreys, 2000). In the modern hospices, pain and symptom control is no longer considered to be instrumental for reconciliation of the soul. Instead, good pain and symptom control are considered conditional for the quality of life of patients.

The variety of needs and wishes of people constitutes the nucleus of palliative care. And because it is acknowledged that there comes a time when life prolongation is no longer important, or even desirable, the quality of life of the people receiving palliative care is the sole criterion for the decisions taken. If cure is impossible and if life prolongation is deemed futile, what remains is to let the patient live until (s)he dies. This implies that the medical realm of care should be fully integrated with the other realms of care. The goals of medical, psychological, social and spiritual care have become the same. Since so much of medicine has underestimated the latter three realms of care, especially these realms merit attention. Psychological, social and spiritual care require professional input. Psychologists, social workers and pastors are members of the caregiving team who are just as important as the physician or nurse.

Understanding the concept of total care requires however four critical remarks. First, the informal care given by the loved ones of the patient is at times more important than the professional care. Care given by informal carers should be given opportunity in palliative care, but without obligating family members to provide such care. Often the patient appreciates this care and for the loved ones of the patient it may give a sense of meaningfulness. The provision of informal care may also facilitate the bereavement process. Second, psychosocial and spiritual care require the autonomous consent of the patient, just as the provision of medical care does. Just like the physician needs the patient to consent before administering a treatment, the other professionals in the team also require the patient's consent and cannot provide care, no matter how well intended, without the permission of the patient (Randall and Downie,

1996). Third, it has to be noted that the idea of total care does not imply that the team is morally responsible for the patient's total well-being. Many patients are only to some extent capable of reaching an emotional, social and spiritual state of well-being (van Duijn, 2000). This may for instance be explained by the personality of the patient or by a lack of informal caregivers. If a state of well-being cannot be reached for the patient, this can be hard to accept for the team. But it does not imply that the team would be accountable if some problems cannot be solved. In this context, a fourth remark ought to be made. In palliative care, the concept of well-being is ambivalent. Despair and hope, anger and courage, acceptance and denial, often go together. Research on the writings of Kübler-Ross indicated that the 'phases' of the dying process are not chronologically ordered but alternate (Quartier, 1999). It would perhaps be more accurate to speak of 'aspects' instead of 'phases'. Total care does not imply that this ambivalence should be eliminated. Total care instead aims at supporting patients and loved ones in order to make the range of ambivalent emotions which occur tolerable. Well-being of patients and loved ones can be considered as a goal of palliative care, it does however not mean that all suffering should be eliminated.

Concludingly, total care at the end of life implies the integration of the medical, the psychological, the social and the spiritual realms. Man, considered as a unity, is in the centre of care. It is essential to provide room for the range of ambivalent emotions of patients and loved ones. This ambivalence should not be eliminated.

1.2.2. Acceptance of death

As mentioned above, the motivations of the modern hospice movement can be clarified if one situates them in their historical context. Crucial for the history of palliative care were the 1960s when on the one hand enormous technological progress was made in the field of medicine and when, on the other hand, the Voluntary Euthanasia Society flourished in the UK. With both, the hospices felt a moral discomfort. They wanted to provide an alternative. Death in technologically driven modern medicine was looked upon as a defeat of the physician. Cure and life prolongation were the primary goals of medicine. In reaction to this kind of medicine, the Voluntary Euthanasia Society pleaded for legalisation of euthanasia. The motivation of the young hospice movement can be seen as an intermediate position. On the one hand, nothing is done anymore to unnecessarily prolong life and keep the patient artificially alive with extraordinary treatment. On the other hand, intentional shortening of life is

rejected. According to the hospice movement, death is considered as a part of life. Probably, Christian assumptions lie behind what is called the acceptance of death. In Christian philosophy and theology, an essential ground structure of life has always been the principle of hope without which human life is hardly possible (Moltmann, 1966). Hope for an afterlife, the awareness that life is not ended at the moment of death, can provide a good ground for acknowledging that death is a part of life. Acceptance of death in palliative care, in the sense that at a certain stage of illness, nothing is done anymore to hasten or postpone death, is congruent with the Christian tradition and can be clarified from this tradition.

The Christian foundations of the hospice movement also provided a basis for the rejection of euthanasia. Man as God's image may not have his/her life ended by another human being. Man has been given stewardship over God's creation. He has not been given governance, he is not in charge. Eventually, he will have to render account of his deeds to God. Euthanasia is considered a violation of man's stewardship. It is interesting to see how Saunders, in her critique of euthanasia, refers back to the early Christian hospices and to the spirituality of the first hospices for the dying (Saunders, 1960). Life, also the life of the dying, is according to Saunders essentially a pilgrimage. No physician or nurse can be ever able to determine when a pilgrimage has come to an end. Essentially, our pilgrimage is aimed at reconciliation and reconciliation can take place only hours before death. Whereas pilgrims, in the literal sense, were cared for in the early hospices, the new hospice movement cares for pilgrims and pilgrimages in a more metaphorical, figurative sense. Whether or not this argument against euthanasia is ethically valid can be questioned.

2. Empirical dimensions of palliative care

The concept of palliative care can only be properly understood in the context of a concrete practice. Understanding the philosophy and the original motivations of palliative care is one thing, but it is more difficult to relate these motivations to a concrete practice in which a concrete patient with concrete needs and wishes is central for a concrete team of caregivers. Concepts such as quality of life, human dignity and acceptance of death are not well equipped to solve the ethical dilemmas that occur in daily practice. Moreover, in order to clarify the concept of palliative care, it needs to be situated in the context of a concrete society. The concept of palliative care is not only influenced by the health services of a specific country, also political, social, cultural and economical

factors are at stake. Palliative care is not a univoque concept but a concept that can adopt a variety of practical and theoretical forms which can be made explainable through research in the societal context of the practice in which the concept is used.

2.1. Organisational forms of palliative care

The historical origins of palliative care can be found in the hospice movement. Since 1974 however, palliative care has been increasingly integrating in already existing institutions of the formal health care system. In the beginning of the 1980s, palliative care was introduced on the European continent. The historical development of palliative care in various European countries has proceeded in similar ways, starting with individual, isolated initiatives which after some time gained cultural and political interest and acceptance. The history of palliative care in Germany for example has recently been summarised by Kirschner (Kirschner, 1996). It is reflective of the history of palliative care in many other European nations. In 1971, a documentary on the young British hospice movement was broadcasted. In the debate that followed the term 'death clinic' was used to denote hospice and the impression was that hospices would isolate the dying from society. In 1978, a questionnaire demonstrated that no less than 92 % of the respondents rejected the foundation of separate institutions for the care of the dying. Palliative care should be given more attention in order to achieve a dignified dying process for patients. But it should be done in the context of acute hospitals and home care, not in the in-patient hospice. The rejection of hospices by the majority of the German population can be explained through insufficient interaction with experiences from hospices abroad. What is perhaps more important however is the mistrust felt by many physicians towards the new concept of palliative care as the hierarchical structures of general medicine, together with its tendency to actively treat patients, were questioned by the hospice caregivers. The introduction of the hospice concept relied therefore on individual initiatives of strong personalities. In 1983, the first palliative care unit was founded by miss Jonen-Thielemann, with the help of the German Cancer Society, at the University hospital of Cologne. The unit counted only five beds and was situated at the top floor of the hospital. In the mid 80s, some further initiatives were developed but all in relative isolation. Because of these initiatives, gradually an attitude shift started to take place in German society. The concept of hospice became increasingly accepted. In the beginning of the 1990s, the German Health Ministry supported the foundation of 12 palliative care institutions. In 1996, the first congress of the German Association

for Palliative Care (Deutsche Gesellschaft für Palliativmedizin, established in 1994) was organised in Cologne, close to the University hospital where it all began. In 1996, Germany counted 26 palliative care units, 30 hospices, 268 home care services, and 183 hospice initiatives (Illhardt, 1999). Clearly, palliative care in Germany has developed at rapid speed. However, whereas the UK in 1996 counted 60 palliative care institutions per million inhabitants, Germany only counted 7.

In the Netherlands, developments in palliative care have profited from social and political support only since the beginning of the 1990s. The first hospice to open its doors in 1991 was the Johannes Hospitium in Vleuten. The debate on hospice and palliative care has been analogous to the debates in Germany. In the same year in which the first hospice was established, an article was published in the journal of the Dutch Medical Association which reflected the opinion of many Dutch physicians. The author stated that hospices and separate palliative care institutions did not meet the needs and wishes of patients and loved ones. Instead of separate institutions, palliative care should be integrated in the formal health care system (Coene, 1991). In the years following, some initiatives, depending on individuals, were developed. In 1994, the hospice Rozenheuvel in Rozendaal opened its doors. This hospice gained wide public interest in the Netherlands and abroad (Enklaar, 1999).

When palliative care was introduced on the European continent, a variety of organisational forms was adopted. Thus, the first palliative care units were established together with home care services, hospices, and consulting teams. Almost all European countries have official associations for palliative care by now. In 1988, the European Association for Palliative Care (the EAPC) was established which currently has over 15.000 members. If one overlooks the history of palliative care on the European continent, the development has been enormous. In Belgium for example, the first palliative care unit was established in 1985. At the end of the 20th century, Belgium counts 50 palliative care units, spread all over the country (Broeckaert, 1999). Italy counted in 1995, 150 palliative care units (SICP, 1995). The Netherlands counted in 1997 6 professional hospices, 3 palliative care units in nursing homes, one palliative care unit in an oncological clinic, 1 palliative care unit in a hospital and 23 small units in homes for the elderly (NIVEL, 1997). In 1994, the Dutch Association for Palliative Care, the so-called *Netwerk Palliatieve zorg voor terminale patiënten in Nederland*, was established. Most palliative care organisations and institutions are member of this association. Self-evidently, the UK surpasses all European countries with its 218 hospices and a total of 3185 beds (Clark, 1999).

2.2. Conceptualisations of palliative care

The variety of institutions providing palliative care goes hand in hand with a variety of conceptualisations of palliative care. It is likely that people working in a home care service look upon palliative care differently than people working in a hospital or a professional hospice.

The media debates on palliative care in a variety of western European countries reveal many similarities. On the one hand it is argued that medicine has changed during the last decades. More attention is now given to the variety of needs and wishes of the patient. The limits of medicine are more and more acknowledged. Death is said to have become accepted as a part of life which does not always have to be postponed. Especially within mainstream medicine, it is argued that palliative care has already become an integral part of medicine. But on the other hand, it is also argued that mainstream medicine still undervalues the care for the terminally ill, that mainstream medicine continues to favour a curative and activistic paradigm, that the idea of total care is still insufficiently present in the hospitals and nursing homes and that pain and symptom control are underestimated areas of expertise. This argument would imply that medicine does still need impulses from outside centres of expertise which, through consultation and education, can be used to improve palliative care in the formal health care system.

The development of palliative care is still rapid in many countries, especially in the context of the formal health care. In 1979, there were already policy documents in Sweden, rejecting the establishment of independent hospices. Swedish physicians were critical of the religious foundations of the British hospices (Valverius, 1999). In Spain, a hospice movement is non-existent, although many of the Spanish pioneers had received their education in British hospices (Gracia and Núñez Olarte, 1999). The UK is an example of a country where palliative care has been integrated in the mainstream health care to a large extent. In 1987, palliative medicine became an official medical specialty. What followed was a growing influence of the National Health Service on further developments in palliative care. This has initiated a debate on the 'specificity' of the concept of palliative care (Clark and Seymour, 1999). Many people working in the area of palliative care were and are afraid of an increasing medicalisation of palliative care which would not do justice to the original motivations of the hospice movement. They are afraid that mainstream medicine, with its focus on cure and intervention, will neutralise the philosophy of palliative care. Others are afraid of a secularisation of palliative care in which most attention is absorbed by medicine and in which spirituality becomes an

underestimated dimension of care. They state that the original charisma of the hospice movement, characterised by a strong spiritual calling and a strong commitment to the humane care of the dying, has gradually become subject of bureaucratisation, medicalisation and rationalisation. Palliative care is said to be in danger of becoming a technique for professional empowerment (Bradshaw, 1996).

The integration of palliative care in the national health care systems has had at least three important consequences. First, the association of palliative care with terminal care, so characteristic for hospice caregivers, is decreasing. The scope of palliative care has widened. Most physicians use a broad concept of palliative care, starting from the time of diagnosis (see chapter 3). A minority is critical, stating that palliative care has shifted the attention away from death (Biswas, 1993). Second, demarcating palliative care from other health care practices has become increasingly difficult and problematic. This invokes the issue of the (moral) 'specificity' of palliative care. Third, the consensus on ethical norms and values underlying palliative care is decreasing. Whereas within the hospice movement a consensus existed on issues such as the validity of the double effect principle, the rejection of euthanasia, the conditions under which medical treatment becomes futile etc., current palliative care is not only integrating in the health care systems, it is also more and more required to involve in the ethical debates within which its values and norms are subject to critique. Clear-cut normative statements do no longer suffice and valid arguments are required.

As mentioned above, one of the normative dimensions of palliative care tells us that nothing should be done to hasten the death of the patient. This normative statement can also be found (even in the indicative mood) in the definition of the WHO. The question is how this statement can be corresponded with the liberal Dutch euthanasia policy. The majority of Dutch physicians is of the opinion that a further development of palliative care can prevent or take away many requests for euthanasia, and that this is one reason why further development is imperative, but that in situations of *force majeure*, euthanasia need not be excluded from palliative care (see also chapter 8). It is too simple to condemn palliative care in the Netherlands for this reason. Not only because also in the Netherlands people are critical of euthanasia, but also because many institutions that do not exclude euthanasia can principally provide compassionate palliative care. (Lack of) empirical evidence does not allow to conclude that the Netherlands are subject to a 'culture of death'. Instead, an open debate, based on adequate arguments, should be aimed at (Wils, 1999).

Be that as it may, in this aspect Dutch palliative care distinguishes itself from all other countries. This explains why only since recently, in the context of an increasing political and societal interest in the further development of palliative care, international co-operation in the field of palliative care has been developed. Dutch physicians, taking part in international conferences, were often forced to render account of their view on euthanasia. The debate on euthanasia and palliative care was extremely polarised and hardly open for objectivity. Currently however, an increasing openness can be discerned. It is widely accepted that palliative care in the Netherlands is not absent and of relatively good quality. A token for this acceptance is the decision by the board of the EAPC to organise its conference of 2003 in the Netherlands. Moreover, it is more and more acknowledged that euthanasia is secretly practised in many countries. Whereas palliative care in the Netherlands can profit from the help from experiences of other countries, other countries may learn from the relatively open euthanasia debate in the Netherlands.

Conclusion

Within a span of thirty years, palliative care has developed rapidly world-wide. The further development of palliative care will create important challenges for many medical specialties. The number of institutions is not of much importance in this respect. From the origins of modern palliative care, it has always been acknowledged that the number of hospices is not important. The ultimate goal has always been the integration of new knowledge and attitudes within mainstream health care. St Christopher's was the first hospice with an interest in education and consultation; this interest has been embraced by the world-wide hospice movement. Indeed it is true that, if palliative care is to develop further, education, consultation, research and proliferation of research results are essential. The future for palliative care will depend on this kind of initiatives. The normative dimensions of palliative care, which have for a very important part been developed within the hospice movement, should however, also in the context of a large variety of health care organisations, maintain their normativity.

CHAPTER 3

CONCEPTS AND ETHICS OF PALLIATIVE CARE

A EUROPEAN COMPARISON

This chapter has been submitted for publication as:
Janssens MJPA, ten Have HAMJ, Broeckaert B, Clark D, Gracia D, Illhardt FJ, Lantz G, Privitera S, Schotsmans P, Concepts and ethics of palliative care. A European comparison.

CONCEPTS AND ETHICS OF PALLIATIVE CARE

A EUROPEAN COMPARISON

Introduction

As part of a European Commission funded project on palliative care ethics (Pallium project), a survey was sent to participants of the Congress of the European Association for Palliative Care (Geneva, 1999). The survey aimed to identify the views of palliative care experts on the concept(s) of palliative care. The assumption underpinning the survey was that the concept of palliative care is not as univoque as is implied in the literature. Rather, diverging ideas on the aims, scope, values, and norms of palliative care might be expected, as well as different opinions on the position of palliative care in the context of the health care system. In this chapter, the results of the survey will be presented and analysed.

The project of which the survey forms a part brings together colleagues with expertise in medicine, ethics, the social sciences, and the humanities from countries with different health care systems and approaches to palliative care. The participating countries are the Netherlands, the United Kingdom, Italy, Germany, Sweden, Belgium, and Spain. The project aims to describe, clarify, and compare various approaches to palliative care. Although palliative care services are now developing across Europe, there is still a scarcity of comparative data, particularly relating to questions of ethics (Clark et al, 2000). Variations in health care systems in different countries imply that the organisational and institutional forms of palliative care may differ considerably (hospices, nursing homes, hospital-based palliative care units). In addition to these organisational differences, views may also vary on the concepts of palliative care, as well as on the underlying moral values and moral norms. Such differences and variations require better understanding if the future development of palliative care in Europe is to be successful. Apart from extensive literature research in national and international debates on palliative care, empirical research is necessary to articulate, analyse and compare the views of experts as regards good palliative care. In the following section, the methods of the study will be described, together with relevant demographical and professional data of the respondents. In the second section, the results of three conceptual queries will be pointed out: terminology, definitions, and the situation of palliative care in the context of society and medicine. Results relating to values and norms in

palliative care will be discussed in the next section. Finally, the results will be evaluated and discussed.

1. Comparative study

Methods

The survey sample was based on the European and Israeli delegates who attended the sixth Congress of the European Association for Palliative Care (EAPC), held in Geneva from 22 to 24 September, 1999. At the congress, the survey was announced by a member of the Board of the EAPC. Delegates who did not want to receive the survey were asked to inform the Organising Committee. The EAPC provided the researchers access to the addresses of those delegates who had not informed the Organising Committee of their objection. The survey was sent in a French version to the French and Swiss participants, and in an English version to all other participants. It was distributed to 2,174 European and Israeli delegates of the conference. From the third of November 1999 until the fourteenth of January 2000, 782 questionnaires were returned of which 14 were unusable. This made a response rate of 35.3 %.

The questionnaire consists of five sections. It starts with questions relating to the demographic and professional data of the respondents (age, profession, institutional setting, nationality, sex). Next come two questions concerning the definition of palliative care. Subsequently, the respondents are confronted with 25 statements to which they could agree or disagree (5 points Likert-scale). The fourth section presents 18 moral notions which respondents are invited to rank according to their perceived importance for palliative care. Finally, the questionnaire presents 14 morally relevant acts, which the respondents are invited to consider.

The results from the total number of questionnaires are presented below, with occasional reference to the seven Pallium countries, considered as a group.

Demographic and professional data

Questionnaires were mailed to 44 European countries and also to Israel (total 45). Questionnaires were returned by respondents from 32 countries. The majority of returned questionnaires represent a limited number of countries: 56.1 % of the questionnaires were received from three countries: Switzerland (21.5 %), France (20.3 %), and the United Kingdom (14.3 %). Belgium, Sweden,

Germany, Italy, Spain, the Netherlands, Poland, Israel, and Ireland contributed together 23.2 % of all respondents. The Pallium countries represent 33.9 % of the respondents.

Two thirds (66.3 %) of the respondents were female. The age of most respondents (89,7%) was between 30 and 60 (with 41.5 % between 40 and 50). Almost a half (46.7 %) of the respondents had a background in medicine, 31.6 % in nursing, 5.9 % in other health care practice and 12.6 % had a different, unspecified background.

2. Conceptual queries in palliative care

Terminology

The respondents typically describe their daily work as 'palliative care' (43.1%), 'palliative medicine' (17.7 %), 'supportive care' (10.3%), and 'palliative terminal care' (3.9%). Only 0.9 percent use 'terminal care' to characterise their work, while 18.9 % use different terms. Respondents from the Pallium countries have even more preference for the labels 'palliative care' (49.8%) and 'palliative medicine' (24.2 %); indeed only one respondent prefers 'terminal care' (0.4 %).

Apparently, the respondents agree that the scope of their professional fields is wider than just the terminal phase, as argued in the literature (Ahmedzai, 1993). This is also shown by the fact that the majority of respondents agree with the statement that palliative care begins from the time of diagnosis (59.8 % total, 67.2 % Pallium countries) and by the fact that a minority agree with the statement that in palliative care nothing is done to prolong life (34.9 % total, 20.4 % Pallium countries). Just under a half (44.4 %) hold that palliative care begins when cure is no longer possible.

Definitions of palliative care[1]

In 1987, when palliative medicine was recognised as a medical specialty in the United Kingdom, the following definition was developed: 'palliative medicine is the study and management of patients with active, progressive, far-advanced disease for whom the prognosis is limited and the focus of care is the quality of life' (Doyle et al, 1996, p. 3). Three years later, the World Health Organisation

[1] The respondents were explicitly informed that the survey questionnaire would use the term 'palliative care', irrespective of their answers with regard to the terminology they use.

developed a definition of palliative care, not only meant for medical doctors but also for other members of the caregiving team: 'palliative care is the active, total care of patients whose disease is not responsive to curative treatment. Control of pain, of other symptoms, and of psychological, social, and spiritual problems is paramount. The goal of palliative care is achievement of the best quality of life for patients and their families' (World Health Organisation, 1990, p.11).

In the survey respondents were invited to identify the definition they use, with the two definitions quoted here provided in a footnote. The majority (67.2 %) of those responding use the WHO definition of palliative care; 15.8 % use the UK definition of palliative medicine, and 14.5 % use other definitions. In the Pallium countries, 75% use the WHO definition.

Palliative care in the context of medicine and society

The survey invited responses to 24 conceptual statements. These statements were ordered at random, though, based on an interpretation of responses, they can be divided into three domains: integration, medicalisation, bureaucratisation.

- Integration

The statement that palliative care should be fully integrated within mainstream health care is accepted by most respondents: 84.3 % agree or strongly agree. At the same time, over a half (53.4%) disagree about whether palliative care should be an alternative to mainstream health care, with almost a third (31.6 %) agreeing or strongly agreeing. A variety of views exists however about whether palliative care should retain a degree of independence from the health care system (6.4 % strongly agree, 27.7 % agree, 28.8 % disagree, and 18.4 % strongly disagree). At the same time, more than half of the respondents (52.7 %) accept that palliative care entails specific values, other than mainstream health care.

- Medicalisation

Various recent publications have addressed the issue of medicalisation of palliative care (Bradshaw, 1996; Clark and Seymour, 1999; Field, 1994). Do experts in the field also have the idea that palliative care is transforming into a medical discipline in which multi-facetted problems of patients are approached with a medical paradigm? Around one half (51.9 %) of the respondents agree that palliative care is becoming medicalised in his or her country, with just 15.6 % disagreeing. One half (50.5 %) agree that the role of the nursing profession is generally underestimated in palliative care, whereas 30.4 % disagree. The idea

that the autonomy of professionals other than the medical doctors is threatened in palliative care has been observed by James and Field (James and Field, 1996). Despite the fact that only a minority of the respondents (31.6 %) have a professional background in nursing, only 18.7 % of the total agree with the statement that the role of the medical profession is overestimated whereas 55.0 % disagree or strongly disagree. The belief that the primary goal of palliative care is the achievement of the best quality of life for the patient is almost universal in the sample (97.8 %) as is the belief that medical, psychological, social and spiritual care are of equal importance (92.4 %). Both of these sets of responses reflect the respondents' resistance to medicalisation.

- Bureaucratisation

In the literature, the potential danger of bureaucratisation of palliative care - the process of transforming individual action into rational, administrative and hierarchical institutions – is discussed (James and Field, 1992). Only a minority of 21.4 % agree with the statement that palliative care is increasingly bureaucratised due to regulations from the health care system, whereas 37.8 % disagree or strongly disagree, with 39.2% who 'didn't know'. Apparently, bureaucratisation and medicalisation do not go hand in hand.

3. Values and norms in palliative care

As was shown, the majority of respondents take the view that palliative care implies a specific set of values, different from other health care practices (52.7 %). Yet only 13.0 % agree with the statement that palliative care entails a religious set of values. Only 14.3 % respond that palliative care *should* do so. A rather larger minority (30.6 %) hold that palliative care has a surplus value compared to mainstream health care. Apparently, for most respondents, the specificity of the values of palliative care is not based on religious beliefs and the majority hold that palliative care cannot claim a moral surplus.

In addition the respondents were presented with 18 moral notions and asked to rank their importance. The notions were selected because of their prevalence in the literature on palliative care as well as in the medical ethical literature in general. Notions with connotations of communitarianism (for instance sympathy, solidarity and compassion) were combined with notions that are often used in the libertarian tradition (for instance autonomy and nonmaleficence). Respondents were invited to indicate whether they thought the notions were extremely important, important, quite important or not important

for palliative care practice. The majority of notions are considered extremely important or important. As Table 1 shows, the ranking of the notions according to the degree of importance is different.

Table 1: The importance of moral notions in palliative care

Ranking of moral notions as important and extremely important (% of respondents)
Quality of life (97,5)
Human dignity (96.2)
Acceptance of human mortality (92.7)
Total care (91.3)
Nonmaleficence/to do no harm (84.3)
Authenticity (84.1)
Autonomy (81.0)
Empathy (80.7)
Beneficence/to do good (78.2)
Hope (74.7)
Solidarity (64.9)
Compassion (64.7)
Prudence (64.2)
Holism (63.1)
Justice (61.9)
Love (50.7)
Sympathy (40.8)
Sanctity of life (30.8)

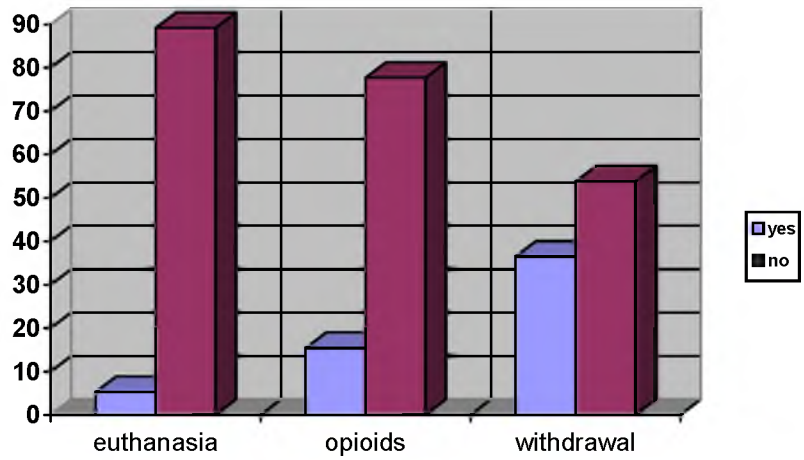
Finally, the respondents were presented with 14 acts and were asked whether or not each of these acts could be a component of palliative care. It was noted on the questionnaire that even if the act would be conceived of as a means of last resort, to be used in exceptional circumstances only, the act should be considered as a possible part of palliative care.

- Active euthanasia

Only 5.3 % of the respondents can conceive of situations in which euthanasia could be performed in palliative care. Interestingly, 15.4 % agree that the intentional shortening of life by raising opioid doses could form a part of palliative care, whereas 36.5 % of respondents accept that the intentional shortening of a patient's life by withdrawing treatment could be part of palliative care (Diagram 1).

Diagram 1: Life shortening medical decisions

Percentage of respondents agreeing or disagreeing with life shortening medical decisions being part of palliative care (Euthanasia = active euthanasia, opioids = intentional shortening of life by raising opioid doses, withdrawal = intentional shortening of life by withdrawing treatment).



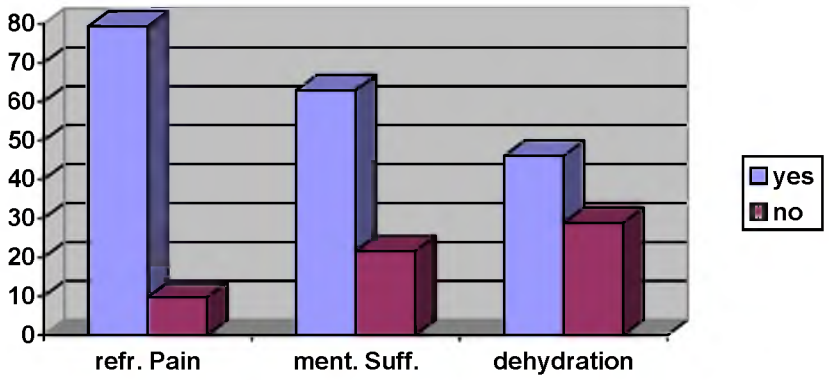
- Terminal sedation

Distinctions have been made between terminal sedation for refractory pain, terminal sedation for relief of mental suffering, and dehydration in the heavily sedated patient. Terminal sedation for refractory pain can be part of palliative care according to 79.3 % of the respondents. Approval of terminal sedation for relief of mental suffering is less marked however, accounting for 62.9 %, whereas dehydration in the heavily sedated patient is approved of by 46.0 %

which is still more than the 28.8 % who disapproves of this practice within palliative care (19.5 % did not know with 5.7 % missing) (Diagram 2).

Diagram 2: Terminal sedation

Percentage of respondents agreeing or disagreeing with terminal sedation being part of palliative care (refr pain = terminal sedation for refractory pain, ment. Suff. = terminal sedation for relief of mental suffering, dehydration = dehydration in the heavily sedated patient)



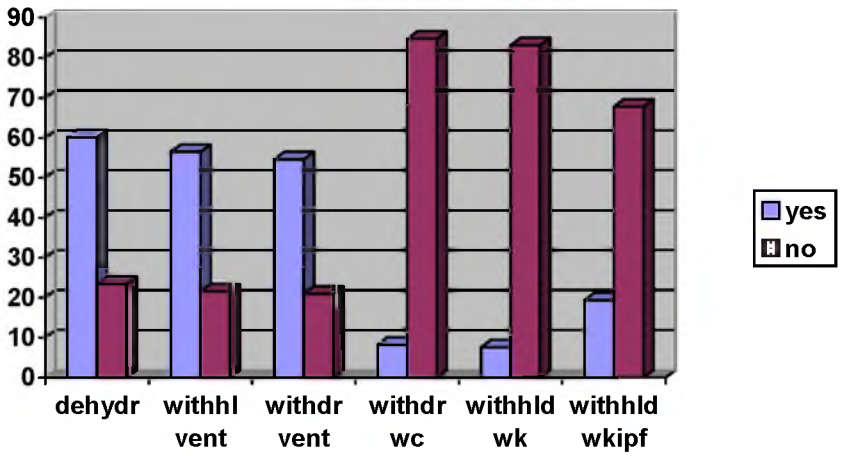
- Withholding and withdrawing treatment

The vast majority of the respondents make no moral distinction between withholding treatment and withdrawing treatment. The difference between the respondents who do not consider the withdrawal of life prolonging treatment without the consent of the competent patient a part of palliative care and the respondents rejecting the withholding of life prolonging treatment without the consent of the competent patient is 1.6 %. Only a minority agree that life prolonging treatment can be withheld or withdrawn without the consent of the competent patient (7.6 %; 8.3%). More respondents (19.4%) can conceive of situations in which life prolonging treatment is withheld without the knowledge of the incompetent patient's family. These findings indicate the importance of autonomy in palliative care (the notion of autonomy itself was considered extremely important or important by 81.0 % of respondents). To the statement that in palliative care, it is sometimes necessary to overrule the patient's

autonomy in the patient's own interest, 60.8 % disagreed or strongly disagreed, whereas 18.9 % agreed or strongly agreed. For the Pallium countries disagreement with this statement was lower (47.6 %) and agreement was higher (29.8 %), whereas withholding treatment without proxy consent was considered a potential part of palliative care in 29.4 % of the Pallium-countries respondents. Interestingly, the respondents from the Pallium countries also were more likely to accept situations in which treatment is withheld or withdrawn without the consent of the competent patient (11.3 %; 11.7 %).
It is remarkable that over 20 percent of the respondents accept that dehydration, withdrawing the ventilator, and withholding the ventilator should not be part of palliative care. For the Pallium countries these three percentages are respectively 20.5 %, 13.6 %, and 15.5 %. (Diagram 3)

Diagram 3: Withholding/withdrawing treatment

Percentage of respondents agreeing or disagreeing with withholding/withdrawing treatment being part of palliative care (dehydr. = dehydration; withhl vent = withholding the ventilator; withdr vent = withdrawing the ventilator; withdr wc = withdrawal of life prolonging treatment without the consent of the competent patient; withhld wk = withholding life prolonging treatment without the knowledge of the competent patient; withhld wkipf = withholding life prolonging treatment without the knowledge of the incompetent patient's family).



4. Discussion

For many respondents, palliative care is now the term of preference to denote their professional realm. Palliative medicine, a term which denotes a medical specialty, and not so much the multi-disciplinarity of palliative care (Doyle, 1993), is probably mostly used by the medical professions. But, taken the 46.7 % of respondents with a medical background into consideration, the term palliative medicine is still only used by a minority of medical doctors.

The vast majority of the respondents think that palliative care should be integrated within the mainstream health care structures. Palliative care should in other words be delivered in the context of hospital wards, nursing homes, general practice, home care services and so on. Paradoxically, according to a substantial amount of respondents of this group, integration of palliative care does not mean that palliative care should not be an alternative to mainstream health care. Neither does integration mean that palliative care would not entail specific moral values, other than the values of mainstream health care. Apparently, adherence to a specific set of values of palliative care can go together with integration in the mainstream health care system. In this respect, notions such as authenticity and hope may be clarifying (see chapter 6). It should be noted that (re-)integration of palliative care has been a goal of the hospice movement from the beginning. From 1967 (when Cicely Saunders established St Christopher's Hospice in London), the main goal has always been to transfer the hospice philosophy back into the wider health care system (Saunders et al, 1981).

Adherence to specific values of palliative care is also demonstrated in the identification of moral notions. Notions such as quality of life, acceptance of human mortality, and total care are considered important or extremely important by over 90 % of the respondents whereas for instance the four general moral principles of biomedical ethics (autonomy, beneficence, nonmaleficence and justice) are all ranked considerably lower. Three out of the four notions which are evaluated as most important (quality of life, total care, acceptance of human mortality) all refer to the definition of palliative care of the WHO and can be said to reflect a specific characteristic of palliative care. For the majority of the respondents, this specificity does not imply a moral surplus in comparison to the values that prevail in the context of mainstream health care, - a finding that has been argued for by others (Randall and Downie, 1996).

Lower ranked notions reflect more general views of good medical practice. Notions that are considered less important (lower than 60 %) reflect either emotions with connotations of the private sphere (love, sympathy), or

notions with explicit connotations to the Christian tradition (sanctity of life) (Hamel and Lysaught, 1994). Notions with less strong, perhaps implicit connotations to the Christian tradition (human dignity, hope, prudence) are rated variably. This finding is corroborated by the small percentage of respondents who believe that palliative care implies an explicitly religious set of values.

Wider concerns within palliative care are expressed through the fact that many believe that palliative care is medicalising (51.9 %) and that the role of the nursing profession is underestimated in palliative care (50.5 %). When we consider that 97.8 % see the best quality of life for the patient as the primary goal of palliative care, that 92.4 % think that medical, psychological, social and spiritual care are of equal importance, and 97.5 % think that the notion of quality of life is important or extremely important, it becomes clear that the supposed process of medicalisation touches at the heart of palliative care. After all, medicalisation implies an overestimation of the medical realm at the cost of other realms included in the concept of total care and in the idea of quality of life.

With regard to moral norms in palliative care, it is striking that for a substantial number of the respondents, intentional life shortening decisions can be part of palliative care. According to the majority of this group, active euthanasia is not one of these. However, at the same time, slightly more than 10% of the respondents agree that there is a crucial moral difference between active euthanasia and the intentional shortening of life by raising opioid doses, a difference that is refuted in the literature (Crul, 1999). More than 30 % perceive a crucial moral difference between active euthanasia and the withdrawal of medical treatment with the intention to shorten the life of the patient. The question here is on what moral basis can specific life shortening decisions be included in palliative care, and active euthanasia excluded.

With regard to terminal sedation, refractory pain is for more respondents an acceptable motive for its use than mental suffering. Dehydration in terminal sedation is common practice in some countries, but less common in others. No less than 28.8 % of the respondents indicate that, even in the most extreme circumstances, dehydrating the terminally sedated patient cannot be part of palliative care; an issue that was extensively discussed some years ago (Craig, 1994; Ashby and Stoffell, 1995; Craig, 1996). An underlying argument may be that the practice seems hard to justify with the principle of double effect; it carries at least the suspicion of resembling 'slow euthanasia'. A similar argument can be raised against terminal sedation for relief of mental suffering. If we assume that it is difficult to assess refractory mental suffering, terminal sedation may easily be considered a disproportionate treatment, also not

defensible by the principle of double effect (Billings and Block, 1996; Mount, 1996; Portenoy, 1996).

Withdrawal and withholding of medical treatment, whatever the nature of the treatment, are considered to be a potential part of palliative care by the majority. Yet, it is remarkable that a substantial 20 % of the respondents do not consider the withdrawal/withholding of the ventilator and of nutrition and hydration a part of palliative care. Perhaps, withdrawal of these medical treatments is associated with an inhumane death, even though in the literature, little support can be found for this association (Brody et al, 1997; Andrews et al, 1993). Another possibility is that hydration and nutrition are considered components of essential care and not medical treatment. Withdrawal/withholding of these treatments may thus be considered as causing death which, according to some, might from a moral point of view be identical to euthanasia.

The patient's informed consent and the incompetent patient's proxy consent are for most respondents conditional upon the morality of withholding/withdrawing treatment, even though absence of proxy consent (if the patient is incompetent) is considered a possible part of palliative care by more respondents than absence of the competent patient's consent; this is in agreement with the literature (Farsides, 1998; Scott, 1999; Osuna, 1998). Moral differences between withholding and withdrawing of treatment are negligible. However, more respondents from the Pallium countries could conceive of situations in which the autonomy of the patients and their proxies is overruled, even though there is no significant difference regarding the importance of the notion of autonomy as such. It is possible that the moral significance of autonomy and informed consent is different in the southern and northern Pallium countries (Privitera, 1999; Gracia and Núñez Olarte, 1999). If not, the unlikely conclusion must be that, considering the nationality of the respondents, autonomy is of special moral significance in France and Switzerland.

Conclusion

This European survey identified diverging views on the concept(s) of palliative care. Consensus exists on only very few issues. Clarity regarding the scope of palliative care (when does palliative care begin?) is currently absent. Issues such as the medicalisation of palliative care require further attention. There is also a lack of clarity with regard to the moral norms in palliative care. Though it seems easy to draw the line between active euthanasia, increasing pain medication and

withdrawal of treatment, further analysis is necessary to unveil and weigh the intuitions and arguments that underlie the perceived different moral evaluations of these practices. What is the moral relevance of intention for the morality of these acts? What does the passive – active distinction amount to in practice and what are its moral implications? Fundamental ethical debates on medical decisions at the end of life can potentially create more clarity in such issues than is currently the case.

Autonomy is a moral notion that is widely adhered to in palliative care, but more research into the relevance of autonomy as a guiding principle in everyday practice is necessary. Important differences seem to exist across Europe. The question is whether informed consent is as fundamental for practice as it seems to be in theory. Do patients have to be informed that the treatment they receive is palliative? Should 'false hope' be eliminated from palliative care? Is there a duty to know? Such questions are only examples of questions that should receive more attention.

In many countries palliative care has initially been developed through individual action, inspired by religious commitment, outside the context of mainstream health care (Clark, 1998; Clark, 1997). Even though, as we have seen, there was an idea of re-integrating the hospice concept into mainstream health care from the beginning, the relation with mainstream health care was mainly antithetical. The hospice concept implied a criticism of the values of mainstream health care. From the results of the survey, it has once again become clear that palliative care is changing. Most respondents feel that palliative care should be fully integrated into mainstream health care. The religious commitment, so pervasively present in the beginning, is still important, but only for a minority of present-day practitioners. Yet, most respondents do adhere to a specific set of values for palliative care. Integration of palliative care does not, according to many, mean that the hospice philosophy is going to be neutralised. In many countries, caregivers in palliative care will have to find a way to keep doing justice to their innermost motivations in the context of institutions that are part of the mainstream health care systems.

CHAPTER 4

THE CONCEPT OF PALLIATIVE CARE

IN THE NETHERLANDS

A shorter version of this chapter has been accepted for publication as*:
Janssens MJPA, ten Have HAMJ, The concept of palliative care in the Netherlands. *Palliative Medicine* (accepted for publication).

THE CONCEPT OF PALLIATIVE CARE

IN THE NETHERLANDS

Introduction

At present, palliative care is at the focus of interest in the Netherlands. With the help of recent financial input from the government, efforts are being made to improve expertise, expand educational activities and establish regional networks in which the primary, secondary and tertiary health care settings co-operate. Six university centres have been selected that will play a crucial role in the further development of palliative care. These centres employ co-ordinators and palliative care teams that work intra- as well as extramural. Some teams will have beds at their disposal, others focus on consultation. Within these centres, undergraduate and postgraduate educational programmes will be developed. The development of hospices will not be stimulated by the Ministry of Health but some existing hospices will continue to exist as integrated institutions in the formal health care system. Palliative care units inside the nursing homes will be further stimulated. At least on first sight, the future for palliative care in the Netherlands seems to provide reason for optimism.

Important choices regarding the future development of palliative care have been made. The organisational structures through which palliative care will develop for the next years have become clear. Some are happy with the choices that have been made, others are sceptical. In this context, we can speak of an emerging public debate on palliative care. And it is worthwhile to investigate whether in this public debate different conceptions of palliative care can be distinguished.

There is broad agreement on some characteristics of palliative care. Palliative care is interdisciplinary, total care. The loved ones of the patients are involved in the caregiving and are supported after the death of the patient by bereavement services if necessary. Death is said to be accepted as a part of life by the caregivers and not something to be avoided or postponed at all times. It is acknowledged that there comes a time when life prolonging efforts become futile.

Yet, many disagreements also exist, particularly on the acceptability of euthanasia in the context of palliative care. But, it can be argued that even though disagreement on whether (and if so, under what conditions) euthanasia can be part of palliative care is by far the most debated topic, there are also other important disagreements; disagreements relating to the scope of palliative care,

the moral status of palliative care, the history of palliative care and appropriate organisational contexts for the provision of palliative care.

In this chapter, the concept(s) of palliative care in the Dutch debate are examined. In the following paragraph, some issues of palliative care on which there is a consensus will be explored. In the second paragraph, different views on the concept of palliative care will be analysed. In the third paragraph, it will be discussed whether these differences imply different concepts of palliative care or whether there is reason to argue for a single concept of palliative care. The conclusion is that, in spite of important and interesting disagreements, the consensus on the concept of palliative care is in fact larger than may appear on first sight from the often polarised debates in the Dutch media. It will be argued that, in the light of this polarisation, the Dutch debate on palliative care has become somewhat blurred and is in need for a reassessment of the internal goal of palliative care, namely the achievement of the highest possible quality of life of patients and their loved ones.

1. A consensual basis

Most definitions of palliative care in the Netherlands are based on that developed by the World Health Organisation (World Health Organisation, 1990). In 1996, a definition was developed by a working group on palliative care: "Palliative care is the continuous, active, integral care for patients and loved ones by an interdisciplinary team at the time that from a medical point of view cure is no longer an expected outcome. The primary goal of palliative care is the highest possible quality of life for the patient as well as for his loved one(s). The patient is approached as an equal and responsible partner. Palliative care responds to the physical, psychological, social and spiritual needs and is extended to bereavement support" (Working group on palliative care, 1996, unpublished). Other definitions differ only to a small extent.

Comparison with the WHO definition brings small, but yet noteworthy, differences to the surface. Use of the term 'interdisciplinary' reflects, better than the term 'multidisciplinary', the necessity to co-operate and negotiate within the team and resist fragmentation. The statement by the WHO that aspects of palliative care are also applicable earlier in the course of the illness in conjunction with anticancer treatment is deleted. Assumably, the working group which developed this definition choose to demarcate palliative care as clearly as possible. Yet, the definition does not say whether there is a difference between the time in which it is decided that cure is no longer an expected outcome and the time in which the primary goal of palliative care becomes the highest quality

of life. It neglects the question whether there is an intermediary phase in which prolongation of life is a viable criterion, even though the disease itself has become incurable. Another noteworthy difference with the WHO's definition is that the Dutch definition states that the patient is approached as an equal and responsible partner. This may well reflect something of the relatively liberal moral climate in the Netherlands in which autonomy, control over oneself and individual decision- making are deemed highly important. The Dutch definition acknowledges that family members do not necessarily have to be the most important persons for a patient and speaks of loved ones (*naasten*, literally the ones closest to the patient) instead. Finally, while the WHO states in an elaboration of its definition that palliative care neither hastens nor postpones death, this statement is absent in the Dutch definition. One reason for this may relate to the Dutch euthanasia debate. As we shall see below, many participants in this debate hold that the active hastening of death should not categorically be excluded from palliative care (Janssens and Gordijn, 1998).

The Dutch Association for Palliative Care, the so-called NPTN (*Netwerk Palliatieve Zorg voor Terminale Patiënten in Nederland*), acknowledges that a variety of definitions exists and that it will have to develop a working definition in the future. But it describes the following seven characteristics of palliative care (NPTN, 1997).

Palliative care for terminal patients:

1. Addresses the whole human being and his/her intimate surrounding
2. Is provided to persons in the final phases of life
3. Makes the dying process as tolerable and dignified as possible for the patient and his/her loved ones; in the perspective of the approaching end of life, the fostering of peace becomes more and more important
4. Is situated in an adequate material environment which offers a feeling of safety and comfort
5. Lasts for a short period of time
6. Entails integrated (para)medical, nursing, psychosocial and pastoral care and support by professional and voluntary caregivers
7. Makes use of scientific results and experiences in the area of palliative care for terminal patients.

Elaborating on these characteristics it is stated that "palliative care for terminal patients is the continuous, active, integral and personal care for patients in their last phases of life and for their loved ones. The primary goal of care is the supporting of patients and their loved ones in affirming or achieving the highest possible quality of life. The patients and their loved ones are partners in care,

with a responsibility of their own" (NPTN, 1997, p. 4). This statement (it is not considered a definition) is very similar to the definition mentioned above. Note that the term 'responsibility' occurs again and that patients are called partners in care.

The NPTN acknowledges that there are three phases in the treatment and care for patients who are eventually to become terminally ill. The first phase is the diagnostic, curative phase. The second phase is that in which symptoms together with the underlying incurable disease can be treated. This leads into the third, terminal phase. The NPTN aims at the development of care for terminal patients but does not address the question whether palliative care as such can cover a wider area of care. This is why it is called the Network for Palliative care *for terminal patients* in the Netherlands. In most cases when the NPTN speaks of palliative care, there is an additional qualification, like palliative care for terminal patients or palliative care in the terminal phase. An important policy statement on palliative care from the Minister of Health to the Dutch Parliament was also called 'Palliative care in the terminal phase' (Ministerie van Volksgezondheid, Welzijn en Sport, 1996). Another commonly used term is 'palliative terminal care'. This term is used by the so-called semi-governmental commission 'Care Research in the Netherlands' (Zorgonderzoek Nederland, ZON) (ZON, 1997) but also for example by the Dutch Association for Nursing Home Care (*Nederlandse Vereniging voor Verpleeghuiszorg*, NVVz) (Nederlandse Vereniging voor Verpleeghuiszorg, 1998). It can be concluded that, because the area of care covered by palliative care remains still in the open, the Dutch prefer to limit this area of care by using the adjective 'terminal'. Basically, this use of the term is in line with a proposal of an ethical framework for palliative care that was published in the *British Medical Journal* in 1991 (Ashby and Stoffell, 1991). The authors distinguish between a curative, a palliative and a terminal mode or phase. The curative mode is the phase of therapeutic intervention, the palliative mode is characterised by a trade-off between measures aimed at improving the quality of life and measures aimed at life prolongation. The terminal mode is the phase in which death is inevitable and imminent. It is admitted that precise points of transition may not always occur. Some unclarities remain. It is for example not always easy to determine when a patient has arrived in the terminal phase of the disease trajectory and serious mistakes may be made if one attaches a stringent ethical framework to each phase (Ashby and Stoffell, 1995).

As mentioned above, palliative terminal care in the Netherlands has become of topical interest in health care policy. The NPTN gives six reasons for the increasing attention paid to palliative terminal care. First, there has been a

growing acknowledgement that palliative care has been an underestimated area of expertise. Education and training have been insufficient, a shared vision on palliative care has been lacking and openness on the side of caregivers for the problems of dying patients has also been lacking. According to the NPTN, there has been a recent change in attitudes towards suffering and death. Death is becoming less and less a taboo and the realities of suffering are more and more acknowledged in public debate. A second reason why palliative care has gained public interest relates to the increasing awareness that there are limits to the curative capacities of modern medicine. A shift is taking place from acute medicine to chronic care. Because of the increase of technological possibilities, processes of incurable diseases last longer and the duty to relieve suffering, rather than merely treating the disease, is more and more acknowledged. Third, due to demographical changes, the number of patients suffering from incurable diseases is expected to rise in the future. Social networks are weakening and especially the elderly patients are likely to depend on formal care, as care from children or relatives can no longer be taken for granted. Fourth, the NPTN points to the increased autonomy of patients and their families who expect not only medical treatment but also attention for the psychosocial and spiritual aspects of their suffering. Respect for autonomy as a principle is said to be ambivalent. Overestimating its importance may lead to an underestimation of dependency and solidarity with others. But autonomy is still considered an important factor that can explain the recent interest in palliative care. Fifth, there have been important initiatives and developments in the area of palliative care inside as well as outside the Netherlands. Initiatives with regard to pain and symptom treatment, acknowledging the multidimensionality of pain, are mentioned as well as developments initiated by the European Association for Palliative Care. Finally, it is said that the Dutch euthanasia debate has underlined the importance of palliative care. The NPTN is referring to the emerging consensus that a further development of palliative care can diminish the number of euthanasia cases. On the other hand, it is stated that the polarisation of the debate has not been very fruitful for the development of palliative care. The NPTN itself does not take a stance in the euthanasia debate and respects the differences of opinion among its members. The common goal to improve palliative care is shared by all members.

It may be true that the vast majority of patients receiving palliative care are cancer patients. However, the NPTN sums up three other groups of patients that are in need of better palliative care. Apart from terminal cancer patients, these are patients suffering from Aids, patients with acute and short lasting pathologies and patients with chronical diseases in the terminal stage such as

Alzheimer patients, patients suffering from strokes, Parkinson patients, patients suffering from pulmonary emphysema and patients suffering from cardio-vascular diseases. To our knowledge, there are no official figures on groups of patients receiving palliative care. Evidence from other countries suggests that the category of cancer patients is by far the largest; and the most advantaged in this respect (Clark and Seymour, 1999).

All in all, it is safe to conclude that currently, the climate for a further development of palliative care is favourable in the Netherlands. It is widely acknowledged that palliative care has been an underestimated area of care for too long. An acknowledgement of the importance of palliative care seems to be related to recent changes in attitude. These are associated with a changed understanding of the goals of medicine. Apart from cure, relief of pain and suffering are getting more attention. The idea of total care has received wide recognition. It is widely admitted that there comes a time when curative and life prolonging efforts loose their meaning and when quality of life becomes the single goal of medical care. On the other hand, there is reason for concern. Even though the development of educational programmes, in the undergraduate as well as in the postgraduate curricula, is deemed important by all caregivers, principles of palliative care are still hardly taught at the medical faculties and nursing schools (NIVEL, 1996). Furthermore, it is argued by the chairman of the Dutch Patients' Association that incurable patients continue to be abandoned in the context of hospital care (Bruntink, 1999a). The financial budgets for home care services are too tight to provide adequate palliative care at home, and 70 % of patients thus die in institutions. And, even though the level and the knowledge base of Dutch health care is high, there is an emphasis on what can be done with technological means, instead of what should be done. It appears that there is some ambiguity in the debate. On the one hand it is argued that a paradigm shift is taking place. On the other hand, medicine is still criticised for its biomedically oriented paradigm. And, even though the principles of palliative care are adhered to in theory, there is good evidence that medical practice is slow to adapt to the new challenges and reorientations that lie ahead.

In spite of the ambiguity relating to the degree medical practice has incorporated principles of palliative care, it can be concluded that there is a growing consensus on the contents of these principles. For an important part, these characteristics are in line with general characteristics that are also shared in the international setting. The following characteristics however, may be seen as typical for the Netherlands:

1. The use of the adjective 'terminal' (palliative terminal care, palliative care in the terminal phase, palliative care for terminal patients).
2. The statement *in* the definition of palliative (terminal) care that patients are approached as responsible and equal partners, implying that patients should be stimulated to make individual decisions for themselves.
3. Absence of a definition that excludes the hastening of death from palliative care.

However, there are disagreements relating to other important aspects of palliative care as will be analysed below.

2. Issues under debate

As stated above, because there is no consensus in the Netherlands on the scope of palliative care, the adjective 'terminal' is added. The debate on the scope of palliative care will be further analysed below. Second, if we are to take various accounts of palliative care by caregivers seriously, it is noteworthy that they often describe their work in terms of virtues and emotions or even metaphors; notions not often heard in the formal health care. Some people speak in this respect of a surplus value. Further interpretation of notions used by caregivers to describe their work is imperative and may reveal some disagreements. Third, there is a debate on the most suitable organisational context for the provision of palliative care, if home care is no longer possible. In this respect, especially the status of hospices is under debate. A fourth disagreement concerns the evaluation of the historical development of palliative care in the Netherlands. The question under debate is about whether palliative care is a young discipline which only recently got the necessary attention, or whether palliative care has been part of medical practice for decades. In other words, the disagreement in the Dutch debate on the history of palliative care implies an evaluation of the quality of palliative care provided up until recently. And fifth, there is the national debate on the toleration of euthanasia in the context of palliative care. Even though it may appear from the international literature that euthanasia is practised in the area of palliative care, also on a national level there are fundamental disagreements. It will be argued that these disagreements can partly be understood as disagreements on the quality of palliative care.

2.1. The scope of palliative care

When does palliative care begin? A recent interview with nursing home physician M. Smalbrugge which was published in *Pallium*, one of the Dutch journals for palliative care, carried the title: "You can already begin with palliative care three or four years before death" (Danhoff, 1999). According to Smalbrugge, palliative care is too closely linked with terminal care. The Dutch media, which have given a lot of attention to the Dutch hospices (on television as well as in the newspapers and magazines) have contributed to this development as hospices admit the majority of their patients only in the terminal stages of their illness. As a nursing home physician, Smalbrugge sees the patients over a much longer period of time. He conceives palliative care as the range of care services aimed at the relief of suffering and at making life more comfortable. In the following issue of the journal, several replies appeared. According to a member of the Working Group on Palliative Care of the Association for Oncological Nurses (the working group that developed the definition which was analysed in paragraph 1), Smallbrugge's broad definition of palliative care is bound to end up in unclarity. Basically, any patient in need of care should receive palliative care, if one follows Smalbrugge's interpretation (Elfrink, 1999). Another reaction proposes palliative care to be exclusively aimed at the quality of life, with a prognosis of 12 months or less (Van Duijn, 1999). According to this author, principles of palliative care can be applied in all sorts of medical practices but for the sake of conceptual clarity, the concept of palliative care should have a limited scope on which, ideally, there is a consensus.

Use of the term palliative care appears to lead to unclarity as to the scope of palliative care. Professionals working in institutions where patients are seen for a longer period of time are likely to broaden the scope of palliative care whereas those working in institutions where patients are seen in their last phases of life, are likely to use a more limited definition of palliative care. Because of this unclarity, the adjective 'terminal' is usually added but without defining it in terms of time until death.

2.2. The values of palliative care

As outlined in the introduction, palliative care is developing rapidly. Official health policy favours the development of palliative care within the framework of the formal health care system. Money has been made available for institutions outside the formal health care (hospices) to integrate but the proliferation of

hospices will not be supported by the government. Six university centres will co-ordinate the provision of palliative care in the region and co-operate with all regional institutions involved in palliative care practice. They have been selected because of their educational commitment. It is acknowledged that palliative care has been underestimated in the educational programmes for too long. Furthermore, if the expertise in the area of palliative care is to increase, research programmes will have to be developed and for this, the academic hospitals provide the most appropriate context. The main message is that expertise in the field of palliative care should proliferate through education and increase through research programmes. And, of course, if palliative care is to develop further, the establishment of a knowledge base and the dissemination of expertise are crucial.

However, practitioners in the field argue that something more is necessary for good palliative care. In order to be a good caregiver it is not only important what kind of care is provided, but also how the care is given. In order to be a good caregiver, one needs specific talents that are impossible to teach explicitly. Consider the following quotation: "... In my opinion, good care and good pain control are not the same as palliative care. The patient also needs a warm, beating heart in his neighbourhood. Someone who gives compassion and is able to listen well. Someone who makes clear: you're one of us, we love you, you belong and we are there for you ... Some have it, and others don't ... Capability and disposition are two different things" (Bruntink, 1999a, p. 19). The director of a palliative care centre writes: "It is extremely hard to express the essence of palliative care in language ... Within palliative care ... we approach the limits of material and physical life ... The wonder of birth, life and death, has all to do with mystic ... it is first and foremost experience and emotion" (Van Hooijdonk, 1999, p. 17).

According to many more palliative care practitioners, palliative care requires a specific set of talents. Caregivers in palliative care need virtuousness. And, even though it may be possible to teach some virtues, it is impossible to teach others. Aristotle distinguished between the intellectual virtues and the moral virtues (Aristotle, 1961). The intellectual virtues may be taught. Through medical education, students gain knowledge in the scientific fundaments of medicine and also develop a degree of professional competence. Moral virtues however are developed through experience, over a longer period of time. The moral virtues are based on emotions that, through practice, have been developed into habits or dispositions. They require not only to act in particular ways but also to feel in particular ways. It is noteworthy that such moral virtues are used to describe palliative care. Palliative care is said to have a surplus value

compared to other health care practices (Schotsmans, 1995). The essence of this surplus value may well lie in emotions and virtues such as love, empathy, hope and compassion.

It may be hard to provide compelling evidence for a surplus value of palliative care. The citations mentioned above seem to suggest that caregivers in palliative care do look upon palliative care as an area of care which entails different, broader moral values than regular health care. If that is the case indeed, palliative care would require a moral language that is different from standard medical ethical notions such as autonomy, informed consent and beneficence. Apart from knowledge and skills, palliative care would require that the caregivers are virtuous persons who are emotionally involved in the care for their patients. Others hold, often implicitly, that there is no reason to attribute a specific moral status to palliative care. It is in line with this understanding that palliative care can be explained by already existing medical ethical notions.

2.3. History of palliative care in the Netherlands

When did the development of specialist palliative terminal care begin in the Netherlands? In 1975, plans were implemented to improve the care for terminally ill patients in the nursing home 'Antonius Ysselmonde'. With the financial help of the city of Rotterdam, together with the foundation 'Voorbij de laatste stad' (beyond the last city, established in 1972 and aimed at improving terminal care in the Netherlands) and, in a later period, the Dutch Health Insurance Council (Ziekenfondsraad) various aspects of terminal care (the adjective 'palliative' was not used at that time) were investigated. These included patients' experiences in the transition phase from hospital to nursing home, bereavement support, nursing care in the terminal phase, psychosocial and spiritual aspects of care, necessity of the continuous availability of at least one bed and the need to create a homelike atmosphere. At that time there was a taboo on the issue of terminal care. Terminal care was associated with 'dying hospitals' and a governmental policy was absent. In 1985, F. Biesenbeek, at that time the Director of Intramural Health Care, Nursing Home Care and Care for the Elderly of the Dutch Ministry of Health, called the period after 1975 a period of reversal; a period in which the dying process had become more in the open. After 1975, death and dying had been decreasingly considered as a taboo and society had started to acknowledge its duty to care for the terminally ill (Biesenbeek, 1985). The social process of individualisation, the prolongation of dying processes because of medical technological innovations and the euthanasia debate were mentioned as factors and signs that can explain why

death and dying had become more and more in the open. Hospitals had started to acknowledge their duty to provide adequate terminal care; contacts with the primary care sector were of increasing importance to see whether patients could be transferred back to their homes. In the late 1970s, relations were established within this project with St Christopher's hospice and St Luke's hospice where some researchers spent time to learn from the developments in the UK. It is remarkable that both English hospices were called nursing homes by Biesenbeek. The project ended in 1985. In a report of the project it is stated that: "Good terminal care practice requires specific attention and skills in all health care contexts. The last ten years, interest has been growing in various settings; voluntary groups have been established, a number of nursing homes, hospitals and other institutions are occupied in terminal care. Dying and care for the dying are out of the taboo-atmosphere, partly because of many publications on the subject" (Bruning and Klein Hesselink, 1985, p. 131). After 1985, initiatives were developed to stimulate home care services in co-operation with Antonius-Ysselmonde. In 1993 the first palliative terminal care unit in a Dutch nursing home was opened in Antonius-Ysselmonde. The opening of this unit can be understood in the light of the preceding 20 years in which much experience had been gained in the area of terminal care.

In the early 1990s, time apparently came for palliative terminal care to mature. Two years before the opening of the unit mentioned above, the first high-care hospice had opened its doors, the Johannes hospice in Vleuten. In January 1994, the Hospice Rozenheuvel, one of the most renowned Dutch hospices, started its services. Many institutions were to follow in which specialist, multi-disciplinary palliative care was provided. More physicians had educated themselves in the area of palliative care abroad, especially in the UK. In 1996, the Dutch Association for Palliative Care was established, uniting the recently established institutions. In the same year a policy statement of the Minister of Health indicated the need to further develop palliative care (Ministerie van Volksgezondheid, Welzijn en Sport, 1996). There were two reasons for this statement and both reasons had everything to do with the newly established hospices. The first reason was the suggestion made by members of Parliament that a proliferation of hospices was likely to lead to a reduction of the number of euthanasia cases. The second reason related to questions that were asked by members of Parliament, after a visit of the Minister to the Hospice Rozenheuvel, as to the further organisational development of palliative care in the Netherlands. In other words, the proliferation of institutions providing specialist palliative care in the beginning of the nineties had required explicit policy. It was argued that, even though the general quality of the Dutch health

care is high, there are insufficiencies in the area of palliative care with regard to the expertise (in psychosocial care as well as in pain and symptom treatment), with regard to co-ordination between the primary, secondary and tertiary health care settings and with regard to the necessary resources (in the light of demographical developments). The policy statement initiated a development which has led to the current situation in which palliative care is of increasing importance.

The reason for this brief historical overview is the question whether palliative care in the Netherlands should be conceived of as a young and largely underestimated area of expertise in Dutch society or whether the Netherlands should be seen as one of the first countries to have explicitly adopted palliative care. If we consider the developments of the last five years, it is safe to conclude that palliative care has been on the increase. Yet, it can also be argued that from the time of the establishment of the first nursing homes in the end of the 1960s, a valuable amount of experience has been gained in the care for the dying. Again, the debate on the historical development of palliative care in the Netherlands is not without bias. Physicians affiliated with nursing homes will point to the important role which nursing homes have played for a long time. Yet, especially professionals in the recently developed palliative care institutions have good reason to point to the deficient expertise and the lack of attention for palliative care in educational programmes and they can draw support from the above mentioned statement of the Minister. The question may seem to be theoretical, or speculative but two debatable issues need to be put under consideration. First, an important justification for the existence of independent in-patient institutions providing specialist palliative care is found in the supposed inadequacy of palliative care in the formal health care institutions. And second, caregivers from nursing homes argue that hospices are unnecessary because their experience is sufficient to provide excellent integral palliative care. A citation from a newspaper article (called: "it's pouring with morphine in those hospices") which was published in response to an interview with the Medical Director of Hospice Rozenheuvel (Brandt, 1999) illuminates the bias of the debate: "In the Netherlands there exists no group of physicians with such intense experience with deathbeds and the palliative care involved as the nursing home physicians. Moreover, these experiences of the last thirty years are eagerly interpreted and passed on in the context of the professional educational programme. That's why it is so annoying if Zylicz speaks of the Netherlands as: 'The country where support in dying has only now obtained recognition' " (Keizer, 1999, p. 8). Needless to say that the author is a nursing home physician.

Whether palliative care in the Netherlands should be seen as a young discipline or as an old discipline may be hard to establish. But the debate on the history of palliative care in the Netherlands reflects the diversity in the use of the term 'palliative care', perhaps more than other debates. People working in any specific profession are situated in a history, a tradition which has preceded them. The situatedness of a specialised profession in a historical context partly justifies the existence of that profession. And because there are at least two histories of palliative care, professionals may feel that the justification of the existence of their profession is being challenged.

In line with this outlined debate, one more important disagreement on the concept of palliative care will be pointed out.

2.4. Organisational context of palliative care

There is consensus that palliative care should be provided at the home of the patient if possible. Projects on the use of medical technology at home have received support from many practitioners (Reith, 1999). Currently, the Dutch Parliament is discussing a proposal to make care leave possible. The proposal states that for a period of ten days, this care leave will be paid for according to a percentage of the caregiver's salary. Discussions arise when home care is no longer possible, for example because the informal caregivers are burnt-out or because relatives are practically unable to provide care at home.

It is rather obvious that these discussions are somewhat biased and ideological in character. One's views on the ideal place of palliative care seem to depend on the institution one works in. And especially in the light of the financial input from the government into the development of palliative care, one may even speak of a 'tribal war' (Bruntink, 1999b). In the Dutch health care system, nursing homes have played an important role for a long time. Since 1989, nursing home medicine has been a distinct medical specialty. The Dutch Association for Nursing Home Care (*Nederlandse Vereniging voor Verpleeghuiszorg*) declares that the provision of palliative and terminal care has been regarded as one of the central functions of the nursing homes since they were founded in the late 1960s (Verwey et al, 1998; Baar, 1998). Based on the concept of integral care, a long development of specialisation and differentiation of care has been taking place in the nursing homes. And one of these differentiated areas of care has been palliative terminal care. Recently developed knowledge and skills in the area of pain and symptom control have been put into practice. The principles of hospice care have been adopted in the context of nursing home medicine. This experience has led to an attitude of acceptance of

death as part of life and an acknowledgement of the variety of patients' needs and wishes. Also the patients' loved ones are actively involved in the caregiving. "The culture of care is present in the nursing homes. Not only potentially but also in reality. And more than in other health care institution" (Bruntink, 1999c, p. 10).

Hospices in the Netherlands vary to a large extent. Due to many initiatives of volunteers, a large number of so-called low-care hospices, often called almost-at-home-homes, have been established recently. They depend on private funding, the general practitioners of the patients continue to be responsible for the medical care, nurses from the region are sometimes called in to provide nursing care, and the volunteers, most of whom have followed introductory courses in providing home care, carry some responsibility for everyday patient care. Their aim is to care for patients for whom home care is (temporarily) not available and for whom hospital care is disproportionate. On the one hand they may fill a gap in the Dutch health care system as professional home care services are suffering from tight budgets and rising demands. On the other hand, it can be argued that questions remain as to the quality of care given in these low-care hospices. There is almost no evaluation of the care given by these hospices whereas especially the psychosocial and spiritual problems of their patients may be extremely complex. In this respect, it would be crucial to assess whether patients are in need of professional care which may be impossible to provide in the context of a low-care hospice. It is remarkable that reports given by people working in the low-care hospices reflect the importance of broad notions, not often heard in the context of formal health care: "Warmth, attention and love: that's what it is all about" (Bruntink, 1999d, p. 9).

The number of the so-called high-care hospices is relatively small and currently there is no increase. The discussion about the role of high-care hospices in the Dutch health care system is of present interest but unfortunately rather polarised. People working in high-care hospices often justify their work by pointing to shortcomings in the Dutch formal health care system. According to them, Cicely Saunders' justification of the necessity of high-care hospices is still actual. According to Saunders: "We had to move out so that attitudes and knowledge could move back in" (Saunders et al, 1981, p. 4). Hospice physicians point to the lack of attention for palliative care in the educational programmes. Knowledge and skills in the area of pain and symptom management are said to be insufficient. Medicine is still too eager to treat and prolong life instead of letting the patient be the guide. Many institutional contexts in the formal health care system are said not to be adapted to the provision of palliative care. Some years ago, it was for example argued that the institutional context of the nursing

home is insufficiently suitable to provide palliative care. The bed occupancy rate is high which makes the capacity for crisis-admission limited. Patients often have to wait for weeks until they can be admitted to the nursing home. Furthermore, it was argued that in the nursing homes, terminal patients have to share rooms with chronically ill patients with a longer life expectancy (Zylicz, 1993).

The debate on the best place to provide palliative care is mainly a debate between caregivers from nursing homes and caregivers from hospices. People working in hospices still point to the underdevelopment of palliative care in the formal health care setting, thereby not only referring to nursing homes but also to hospitals and general practice (Enklaar, 1999). And apart from the quality of patient care, they see the high-care hospice as an excellent centre of expertise from which knowledge, skills and attitudes can be disseminated and integrated into the formal health care by way of education and consultation. The suggestion of hospice physicians that the quality of palliative care is deficient in the formal health care institutions is refuted by nursing home physicians. As mentioned, they claim the longest experience in the field of palliative care. Experiences with palliative terminal care units inside nursing homes are said to provide evidence for the superfluousness of hospices.

In the meanwhile, the largest financial resources are now mandated to six university hospitals. Not surprisingly, academical physicians (especially anaesthesiologists and oncologists) have not much interfered with the debate on the best locations to provide palliative care as their 'Centres for the Development of Palliative Care' (*Centra voor de Ontwikkeling van Palliatieve Zorg*) will have to become co-ordination centres taking into account all organisations involved in palliative care in the region. Apart from co-ordinating the provision of palliative care in the region, they will employ palliative care teams. Again, it is questioned by people outside the context of the hospitals whether the hospital environment is the suitable context to provide palliative care. Be that as it may, if one acknowledges that expertise in palliative care should increase and proliferate it seems sensible to take university hospitals as a starting point.

The debate on the adequate organisational contexts for the provision of palliative care is understandable for a country which is only beginning to improve and proliferate expertise in palliative care. At the same time it is questionable whether this debate serves patients' interests. The Dutch Association of Palliative Care rightly does not take a stance and acknowledges that adequate palliative care can be given in a number of different institutions depending on the personal needs and wishes of the patient. And, even though

high-care hospices will be integrated in the formal health care, there is reason to believe that also in the future there will be a place for a variety of institutions, including hospices, providing palliative care.

2.5. Palliative care and euthanasia

Much thought and debate have gone into the subject of euthanasia and palliative care in the Netherlands. In the context of this chapter, let it suffice to point to some salient issues in the national debate, and leave the international debate aside.

In the hospices euthanasia is not provided but, if patients insist, they can be transferred to an institution providing euthanasia. At the time of admittance, 25 % of patients of the hospice Rozenheuvel issued a request for euthanasia if pain and suffering would become unbearable. However, from the 769 patients who have been admitted between 1994 and 1998, only three persisted in their request. Anecdotal experience from hospice practice suggests that in the context of compassionate care the vast majority of requests disappears after some time (Janssens et al, 1999).

Most teams in high-care hospices resist the label 'opponent' with regard to euthanasia. Consider the following citation from a book on hospice experience: "Euthanasia is a means of very last resort I will never use. I have the feeling that I won't be the same anymore after having crossed that borderline. But I will never leave the patient who requests for euthanasia alone and always offer him another alternative. If the patient persists in his decision and does not accept my alternative, I will help him by referring him to colleagues. The difference between administering barbiturates [an accepted means of last resort in hospice practice, RJ] and euthanasia is very small. But it is a borderline I will never cross" (Enklaar, 1999, p. 95). Non-intended effects of treatments which will shorten the life of the patient are under conditions acceptable in hospice practice. But euthanasia is considered a 'Rubicon' (Enklaar, 1999). Accepting euthanasia as an option may hinder the creative process of developing alternative palliative modalities. In this respect, it is significant that whereas terminal sedation is heavily debated abroad, it is hardly a topic in the Dutch debate. Moreover, accepting euthanasia may be dangerous in the light of the often so ambiguous and multi-layered euthanasia requests of patients. Often, in the context of good communication, euthanasia requests may amount to something very different than a request to have one's life ended (Zylicz and Janssens, 1998).

Yet, the majority of Dutch physicians consider euthanasia, under conditions, a possible option in the context of palliative care (Van der Maas et al, 1996). If the pain or suffering of a patient becomes unbearable and if all other alternatives are exhausted, euthanasia is considered a morally justifiable means of last resort. Many will agree that the further development of palliative care is very likely to diminish the number of euthanasia cases and that it is imperative to provide euthanasia only in the context of good palliative care. Many will also agree that the taking of another person's life is at least on first sight prohibited. But in cases of so-called *force majeure*, euthanasia may be the only alternative left (see chapter 8). The Minister of Health reflected in her statement (see above) the opinion of most Dutch physicians that "euthanasia can be a dignified end to good palliative care in the final, terminal phase" (Ministerie van Volksgezondheid, Welzijn en Sport, 1996, p. 9).

In 1997, the Cabinet stated that euthanasia is only justifiable in the context of good palliative care (Dutch Parliament, 1997). Much has been done since to improve palliative care. The current proposal of the Cabinet to officially legalise euthanasia under conditions seems to imply that the Cabinet is now content with the level of palliative care in the Netherlands. But, in the context of all efforts to improve palliative care, that would be hardly consistent (Jochemsen, 1999). Much critique has come especially from nursing home physicians on the Cabinet's opinion on the legal acknowledgement of euthanasia-declarations. Especially the argument that it is necessarily unclear whether incompetent patients still wish to have euthanasia at the very moment in time seems to carry weight. The new legal proposal is at this time still to be discussed by the Dutch Parliament.

In the context of recent developments in the area of palliative care, the national debate on the acceptability of euthanasia has become rather polarised. In a reaction to a newspaper article which was critical of euthanasia (Janssens, 1997), it was stated that the author "... had hit thousands of caregivers right in the face" (Van Dam, 1997, p. 8). In a reaction to another article (Brandt, 1999), it was said that the author makes his colleagues look like fools with a number of 'insulting' remarks on euthanasia policy in the Netherlands. The author stated that the hypocrisy rises to the top if hospice physicians deny that high doses of morphine amount to the same as euthanasia (Keizer, 1999). What is at stake in this debate is not only the question whether euthanasia is an option in palliative care. Also, physicians who accept euthanasia as an option feel that the quality of their provision of palliative care is criticised by people who don't accept euthanasia as an option. They have the impression that the palliative care they provide is ideologically described by critics of euthanasia as being less creative and as

insufficient in the search for alternatives. They argue that the palliative care they provide is being judged and criticised as insufficient *because* they do not reject euthanasia from the outset.

Whereas the debate appears to be on the morality of euthanasia, on second sight an evaluation of the quality of palliative care is also at stake. Again, hospices do justify themselves by pointing to the inadequacy of palliative care in the formal health care system. And indeed, they elaborate on the popular view that the further development of palliative care may diminish the number of euthanasia requests. On the other hand, many professionals in other health care settings claim to have acquired expertise in palliative care over the last decades. They argue that palliative care can never take away all euthanasia requests.

The polarisation of the national euthanasia debate has a lot to do with an evaluation of the quality of palliative care, or health care in general. This is not to say that differences in opinion on the acceptability of euthanasia do not matter. But they alone cannot explain the polarisation.

3. Evaluation: Concept or concepts of palliative care?

What is a concept? According to MacIntyre, concepts derive their meaning from practices (MacIntyre, 1984). And, in MacIntyre's view, practices essentially entail a teleological structure. They are aimed at the realisation of a goal that is internal to the practice. Institutions are instrumental and are aimed at the realisation of external goals of practices such as money and status. They sustain practices and they are the bearers of practices. But, in contrast to institutions, practices are exclusively aimed at goals internal to themselves. If we adopt this teleological line of thinking, it would follow that if there would be a consensus on the internal goal of the practice of palliative care we would be able to speak of one concept of palliative care; if there would be disagreement we would have to speak of different concepts of palliative care. All definitions of palliative care would hold that the internal goal of palliative care is the highest possible quality of life of the patient and his/her loved ones. Palliative care is defined in terms of the patient's and his/her loved ones' well-being.

In MacIntyre's teleological views, internal goals of practices cannot be achieved without exercising virtues that enable us to achieve these internal goals. In paragraph 2.2., this was acknowledged and a distinction was made between the intellectual virtues and the moral virtues. Some people hold that provision of palliative care requires not only the exercise of intellectual virtues but also the exercise of the moral virtues which are formed through many past

experiences and which cannot be taught at school (Bruntink, 1999a; van Hooijdonk, 1999). On second thought, it may be impossible to distinguish the two. Aristotle himself has bridged the distinction by pointing towards the intellectual virtue of practical wisdom (Aristotle, 1961). Without practical wisdom we would not be able to discern the moral good from the moral evil in a particular situation. Practical wisdom provides the link between the moral virtues on the one hand and the morally right application of these virtues in a concrete situation on the other hand. Practical wisdom is the intellectual deliberation that decides how the moral good can be achieved in a concrete situation. Thus, the moral virtues such as courage and justice cannot be conceived without the intellectual virtue of practical wisdom. Practical wisdom needs to be distinguished from the other intellectual virtues such as science and professional competence exactly because of its connection with moral practice. We can possess the intellectual virtue of professional competence but if we do not know how and when to apply it in the right way, it is of little use. Intellectual as well as moral virtues are crucial for good palliative care.

Even though the two sets of virtues invoke one another, we have to acknowledge that professionals in palliative care use different notions to articulate their expertise. Some hold that palliative care cannot be described in ordinary language. They use metaphoric terms like 'mystic', 'wonder' and 'power' to denote their motivations as caregivers. Christian virtues like hope and love are also mentioned. Others limit themselves by the use of descriptive language. But these differences in language are not sufficient to conclude that different concepts are at work. All caregivers share in the goal of achieving the best possible quality of life for their patients. And in doing so nobody can do without certain dispositions that are aimed to achieve this end.

If we bear in mind the debates analysed in earlier paragraphs, it may seem as if the external goals of palliative care have become central whereas the consensus on the internal goal has become forgotten, or blurred. MacIntyre writes that external goods are characteristically objects of competition. The more someone has of them, the less there is for other people. A sceptical recent editorial put it this way: "It seems as if over the heads of the patients a tribal war is being fought. 'We are better than they are ...' It is understandable that such debates belong to the initial phase but ... palliative terminal care should be there where the patient is" (Bruntink, 1999b, p. 2).

Concludingly, there may be more consensus on what palliative care is than some participants in the debates are willing to admit. And indeed, if palliative care is to develop further through co-operation an acknowledgement of this consensual basis is imperative.

Conclusion

There is reason to be optimistic about the future of palliative care in the Netherlands. Until recently, co-ordination, co-operation, education and consultation have been given insufficient attention. Therefore, from the so-called Centres for the Development of Palliative Care expertise will be increased through research and proliferated through under- and postgraduate educational programmes. Co-ordinators attached to these centres will, in co-operation with regional cancer centres, improve the co-ordination between all sorts of settings involved in the provision of palliative care so that regional networks are established. Palliative care teams affiliated with a variety of institutions will have to disseminate their expertise through consultations in the context of primary, secondary and tertiary care settings.

This does not mean that there are no obstacles to be dealt with. From an international perspective, palliative care in the Netherlands has developed in relative isolation, partly due to mutual reproaches with regard to the liberal euthanasia policy. International affiliation, a.o. through co-operation with the EAPC, has only recently been established. Furthermore, it may be difficult to introduce more intensive educational programmes in specialist palliative care. More room for palliative care means less room for other topics and competition is to be expected. Convincing arguments will have to be provided and, especially because some claim to have taught (principles of) palliative care for a long time, this may be harder than would appear on first sight.

I have argued that there is more consensus on what palliative care is than may appear from the debates in which at times external goals appear to be central instead of the internal goal. The internal goal of palliative care is the highest possible quality of life of the patient and his/her loved ones. Palliative care is multidimensional because the needs and wishes of patients and their loved ones are multidimensional. If it can no longer be provided in the home of the patient, it can be provided in the context of a variety of institutions by a variety of professional caregivers. For the future of palliative care, it is imperative to keep the needs and wishes of the patient and his/her loved ones in mind.

Note

* Differences with the published version:
Even though the structure and the main message has remained the same, all paragraphs of this chapter are more extensive than the paragraphs of the article. The main reason for this concerns the number of citations from the literature on palliative care in the Netherlands.

CHAPTER 5

THE NOTION OF PAIN

This chapter is a revised combination of two published articles*:

Janssens MJPA, ten Have HAMJ, Pijn in het morele en publieke debat. *Wijsgerig Perspectief.* 1997/1998: 38; 48-54.

Janssens MJPA, ten Have HAMJ, Die niederländische Debatte über Schmerz und Schmerzbekämpfung in den Niederlanden. Philosophische Grundlagen und medizinische Praxis. In: Gordijn B, ten Have HAMJ, (eds.), *Medizinethik und Kultur. Grenzen medizinischen Handelns in Deutschland und den Niederlanden.* Stuttgart: Frommann-Holzboog; 2000; 197-224.

THE NOTION OF PAIN

Introduction

For a long time, pain has been a stranger inside the realm of medicine. Medicine did not pay much attention to pain and pain treatment. As pointed out in chapter 1, medicine was mainly occupied with cure and life prolongation, sometimes with the help of disproportionate treatments. While the developments in curative medicine were taking place at high speed, new developments in the area of pain treatment were rare. Pain was considered a physical defect caused by an underlying disease or by medical treatment itself. The presence of pain required medical intervention in order to remove it. Thus, pain was situated in a medical-technological framework. Medical ethics did not pay much attention to pain and symptom management either. As it was occupied in securing the autonomy of patients, perspectives on the total well-being of patients were outside its scope. The situation of pain in our culture contains a paradox; whereas pain has become situated in a medical paradigm in which it is considered a medical task to remove pain, medicine has not paid much attention to this task.

In this chapter it will be argued that the understanding of pain as a physical defect is a simplification. Pain constantly escapes from the medical framework in which it is subsumed. It cannot be encapsulated in a medical realm. Time after time, pain frustrates medical attempts to control it. Pain is a mystery.

First, the dominant view on pain will be clarified from a historical perspective, going back to the age of Enlightenment. Second, three phenomenological perspectives on pain that were developed in the Netherlands will be analysed. It will be argued that these perspectives present alternatives to the biomedical perspective on pain. Third, the current debates on pain will be analysed, again focussing on the Dutch context. In these debates, enriching perspectives are beginning to emerge. The debates relate to the area of chronic benign pain as well as cancer pain. Fourth, proposals to further broaden the current understanding of pain and pain management will be discussed. Within these proposals, pain is said to carry potential meaning. Medicine can be one possible perspective to approach pain, but more perspectives are necessary for good patient care. Finally, it is concluded that one of the major challenges of medicine today is to adopt and implement this broader view on pain in everyday practice.

1. Pain in biomedicine

Before Enlightenment, pain was situated in an encompassing socio-religious framework together with perspectives on life and death (Rey, 1993). It was a framework that provided meaning to pain and suffering. For instance, pain could be understood in relation to the pain and suffering of Christ. Pain could lead to purification or reconciliation for committed sins. Within this transcendent framework, pain and suffering were potentially acceptable as a part of life. And their acceptation was facilitated as the understanding of pain and suffering was shared by a community of people.

At the beginnings of the Enlightenment, the self-understanding of the human subject changed. The subject became an 'I'-sayer, a self-possessing self, self-satisfied, creating, or pretending to create, its own norms and values. Wils has pointed out three changes that took place in the Enlightenment period (Wils, 1996). First, a process of individualisation of perspectives on life and death started to originate. The community no longer shared ideas on pain and suffering. The individual became bound to decide for him/herself how to deal with pain and suffering. Second, due to this process of individualisation, a focus on intellectualism can be distinguished which led to a structural feeling of insecurity. Third, as a consequence of these changes, the psychological attitude of human beings became determined by a permanent cautious attitude and an urge for correction and improvement. Illness and death were to be avoided at all cost. Apart from the scientific language of medicine, they could no longer be communicated. Possibilities to attribute meaning to pain, illness and death disappeared. Rather than accepted, illness and death had to be conquered with the help of medicine. Medicine indeed provided the discourse within which communication about pain was possible; a dualistic discourse within which the socio-religious aspects of pain disappeared. Pain was conceived of as a physical evil.

The origins of the dualistic biomedical model can be situated at the beginnings of the period of the Enlightenment. The well-known picture of Descartes of the angelic boy holding his foot near the fire is illustrative for the modern concept of pain (Crul, 1999). In this theory, pain is a demonstrable bodily mechanism. The nerves at the place of the injury send out the pain signals to the brain. In the brain, the pain sensation originates which subsequently stimulates an adequate reaction (e.g. withdrawing the foot from the fire). Within this model, pain is a sensation that is directly caused by external stimulations. The site of the injury can be pinpointed; the pain sensation cannot be conceived of without a concrete, painful bodily site. Pain is thus a symptom of bodily

defects. It is detectable and almost takes the form of a substantial entity. The corollary of this view of pain is that the removal of pain is considered the exclusive task of medicine. It is therefore remarkable and perhaps paradoxical that in the 1960s and 1970s, the years in which the knowledge and expertise in various medical specialties increased drastically due to technological innovations, efforts to improve pain treatment were relatively scarce (Crul, 1997). Publications on pain treatment in the leading medical journals were rare. Medicine was occupied with diagnosis and cure and medical ethics was occupied with securing the autonomy of the patient through the development of ethical guidelines and protocols.

The dualism that has underlied the biomedical paradigm since the Enlightenment has had important implications for the understanding of pain. Three characteristics can be pointed out. First, the paradigm leads to an overestimation of somatic aspects of pain and an underestimation of psychological, social and spiritual aspects. The personal and historical experience of pain cannot be rendered account of. Second, it is considered common-sense that pain requires medical treatment. Pain is something that must be removed as soon as possible. It is an obstacle to a meaningful life. The underlying, implicit ideal is a life free from pain. A third symptom is paradoxical: the biomedical paradigm makes it harder for medicine to become successful in removing pain. It is as if pain itself withdraws from the medical domain through laws of its own that do not respond to the biomedical approach (Morris, 1991). Especially chronic pain seems to resist medicine's urge for control, more than other forms of pain. People suffer from chronic pain, sometimes without the presence of a detectable physiological pathology. Chronic (benign) pain thus challenges our belief in the capacities of modern medicine and in the biomedical paradigm.

Pain has become medicalised. Nowadays, pain only seems to be understandable and communicable within the medical domain; here, pain is understood as a 'negativum', an evil that must be removed. The medicalisation of pain presupposes the ideal of a life free from pain. But, as will be argued in this chapter, the urge to ban pain from life is hubris and, moreover, it is counterproductive. The more we intend to remove pain through medical treatment, the more pain escapes itself from our urge to be in control and the more it befalls us in ways that are incompatible with the biomedical paradigm.

2. Phenomenological perspectives

In chapter 1, it is argued that it is the main task of medical ethics to reveal moral meanings that have remained hidden, for example because dominant discourses exclude them. Let us now in this line of thinking attempt to identify and explore perspectives on pain outside the dominant biomedical perspective. This can be done by analysing the views of three representatives of the phenomenological philosophical tradition in the Netherlands (FJJ Buytendijk, JH van den Berg and W Metz). Some of their views have regained relevancy in the current Dutch debate on pain and pain treatment.

2.1. The views of FJJ Buytendijk

In 1914, FJJ Buytendijk (1887 – 1974) became a lecturer in general biology at the Amsterdam Free University. Five years later, he got a chair in physiology at this University. In 1925, he moved to Groningen and became professor of physiology. During these years, his interest in psychology increased. Through contacts with the German phenomenologists Scheler and Plessner, he began to affiliate more and more with the phenomenological school. His idea was that a synthetic knowledge of living phenomena was to be developed from psychological research, rather than physiological experiments. In 1946, he was appointed as professor of general and theoretical psychology at the universities of Nijmegen and Utrecht (Dekkers, 1985).

In 1943 he published his book *Over de Pijn* (Buytendijk, 1943). It is a synthesis of physiology, psychology, and phenomenology. The structure of the book illustrates the synthetic character. It begins with a general philosophical elaboration of the problematic aspects of pain. The second part of the book discusses the physiology of pain. In the third part, the pain experience with animals is analysed. And in the last part, a phenomenological analysis of pain is sketched out. The philosophical analyses of the first and the final part of the book provide the framework for physiology and psychology.

Buytendijk points out that modern man suffers from an algophobia. Pain only appears under the perspective of fight. Medicine is held responsible for the control of pain. The presupposition is that pain has to be taken away through medical interventions. This algophobia of modern man makes it difficult to reflect on the meaning of phenomena. Buytendijk calls the modern, dominant perspective on life a bourgeois, conventional attitude. The real questions with regard to the meaning of phenomena such as pain are no longer taken into account. While the emphasis is on impersonal objectivity, hardly any attention is

paid to the metaphysical, religious and moral dimensions of the problem of pain. However, the experience of pain itself appeals to us with a particular urgency to reflect on its nature and meaning. According to Buytendijk, not experiences of lust or happiness which fulfil us immediately, not the feelings of unease which come from outside and force us to react actively and appropriately, not mental suffering which is characterised by a relative vagueness and unclarity, but only the experience of physical, persistent pain almost forces us to reach out for a deeper meaning. Exclusively in physical pain, Buytendijk argues, we are experiencing the radical separation between our personal and corporeal being: "*My* hand is hurting, *my* head is hurting" (Buytendijk, 1943, p. 29). In agreement with his friend Max Scheler, Buytendijk emphasises that continuing pain takes away our metaphysical ease ('Leichtsinn') and forces us to ask for the meaning of this evil (malum). Whereas acute pain makes modern man ask for its relief, its conquest, continuing, chronic pain urges man to ask for redemption.

According to Buytendijk, insight in the problematic nature of pain cannot be gained without a more detached physiological and psychological method. Physiology can give pain its proper form, amidst other phenomena of life. The psychology of pain is discussed, particularly regarding the question whether pain should be conceived of as an affection (a body part being touched), or a feeling (a more general situation of being). He admits that pain has characteristics of both but with regard to severe and persistent pain, the apparent dichotomy must be transcended. This kind of pain does not only concern our body but also our person and in a deeper and more intense way than other affections and feelings. That is why we usually speak of 'suffering' pain. Suffering pain is a typically human phenomenon because it implies a relationship. In persistent pain, this relationship is characterised by feelings of helplessness and powerlessness towards the pain. The presence of pain forces us to answer the question for its meaning while at first sight no answer can be given. Still, it is in this relational aspect of pain that the potential meaning of pain can be located, a meaning of an existential, metaphysical nature. It can take the form of heroism or of equanimity but Buytendijk seems to indicate that these attributions of meaning are imperfect; pain asks for a fuller, deeper meaning. He thus argues that only when the pain sufferer is situated in the context of the solidarity of a community, such meaningful perspectives can originate. The pain of one person is transformed into a symbolic reflection of the situation of existential despair of all people. The pain sufferer is brought closer to him/herself *in* his/her fragility and participates in the situation of despair of the entire community. And acknowledging this general despair is the starting-point for the promise of a better world.

At the close of his book, Buytendijk presents an account of a (possible) Christian perspective on pain. In this view, pain acquires the deepest meaning in relation to the forgiving love of God who allows man to proceed on his/her Calvary.

2.2. The views of JH van den Berg

The neurologist JH van den Berg (born in 1914) regularly met with Buytendijk at the time the latter lectured in Utrecht (1946-1957). Although Van den Berg was a professor at Leiden University, he belonged, together with Buytendijk to the so-called Utrecht School, which was characterised by its phenomenological methods in psychology (Dekkers, 1985).

Van den Berg became well-known because of what he called 'metabletika' (metabletics, or the study of changes). He is interested in historical texts which at one time in history seemed to contain self-evident meaning but astonish the modern reader. Such texts reveal changes in human existence. Metabletically significant texts indicate changes in the reality of life itself (Van den Berg, 1959). The booklet *Medische macht en medische ethiek* (Medical power and medical ethics) that was discussed in chapter 1, can be seen as an example of metabletics.

In another publication, *Leven in meervoud* (Life in plural), Van den Berg describes the changes which took place at the end of the eighteenth century. Van den Berg shows that through these changes, man has become alienated from him/herself. He argues that from the end of the eighteenth century onwards, a process of increasing pluralities has taken place in human existence; a division of labour (Marx, Durkheim), a division of the human psyche (origins of psychiatry), a division of matter (origins of modern natural sciences). From this time onwards, it is no longer possible to speak of a single self of man. Man has fallen apart into a plurality of identities. His experiences in the social context have become 'paratactical' which means that social experiences have become chaotic, incoherent. We have become determined by a plurality of social contacts. With each contact corresponds a specific identity. Van den Berg explains the origins of modern psychiatry and psychology at that time through the necessity of a variety of identities. Paratactical experience has moreover caused the development of psychosomatic illnesses. In this context Van den Berg also mentions pain: "When the paratactical relation between two or more people has taken the shape in which the ... proper self of one of the participants is more or less avoided, pain originates in him. Headache, backache, stomach-ache, pain in the limbs, all this, although not at the same time, is the price for the

abandonment of the proper self" (Van den Berg, 1959, p. 247). In the nineteenth century, the intensity of pain increased because at that time life was already lived in plural. The alienation and the chaotisation which took place in this century, explain the increase in the intensity of pain. The division of labour has led to estrangement on the side of the labourers with regard to the product of their labour. The more labour became divided, the more painful pain became. In other words, if one only would be able to devote oneself to an object, and to resist alienation, pain would become less intensive. As an example, Van den Berg cites Kant who suffered from gout but was able to suppress the sensation of pain by "a strong devotion to an arbitrarily chosen object, whatever it may be" (Kant, 1959; Van den Berg, 1959, p. 186). He also points to situations of war, in which soldiers had become immune to pain because they could devote themselves to anything that belonged to the enemy.

In 1778 hypnosis was made public in Paris by the Viennese physician Mesmer. In Paris, a group of researchers was established under his supervision. Within this group it became rapidly known that hypnosis can create a situation of insensitivity to pain. But only in the year 1829, the first surgical operation was carried out under (Mesmerian) hypnosis. In the year 1799, the narcotic effect of laughing gas was made public and in the year 1818 the narcotic effect of ether. But it took until 1845 before a surgical operation under ether narcosis and a surgical operation with laughing gas was first carried out. "Why not earlier?" Van den Berg asks. The answer is that there was no need. Because only between 1780 en 1840 the intensity of pain started to increase. In other words, narcosis and hypnosis were not carried out yet because only in 1780 the processes of alienation, chaotisation and pluralisation of human existence originated.

2.3. The views of W Metz

In 1964, W Metz (1909 – 1995) wrote a thesis entitled *Het verschijnsel pijn. Methode en mensbeeld van de geneeskunde* (The phenomenon of pain. Method and anthropology of medicine) (Metz, 1964). Although Metz was not a philosopher by training, he was teaching medical philosophy at the Amsterdam Free University from 1976 to 1982. His publications were inspired by phenomenology.

In his thesis, Metz argues that for the last three centuries, medicine has been determined by a specific scientific paradigm. Its anthropology and methodology have been adopted from the natural sciences. Medicine has become nothing more than applied natural science. The basis of this medical

anthropology is derived from Cartesian philosophy. The separation Descartes made between 'res extensa' and 'res cogitans' and the separation between a scientific world, in which all thinking is objective, and a subjective world, in which it is impossible to distinguish between truth and non-truth, has created a radically dualistic theoretical framework with wide ranging consequences for medicine. According to Descartes, the body can be situated as an object in the scientific world. Since Descartes, the body has received a scientific status. And later on, in the early period of modern psychology, also the soul was attributed a scientific status.

This development however, in which more and more dimensions of human life become situated in a scientific framework, is according to Metz nothing more than a speculative philosophical hypothesis that, when applied, unavoidably leads to flaws. These flaws can be illustrated by looking at the area of pain and pain management. If one considers man in this area as a solitary, physical entity and excludes the influences of the societal context, the failure of the physiological perspective will reveal itself. For how can pain without any detectable physiological cause be explained in such a paradigm? This problem makes clear that physical pain cannot be fully understood within a dualistic paradigm. The phenomenon of pain indicates that medicine is not a science but an art, based on experience. Medicine should be understood from the perspective of the 'Lebenswelt', the 'life world', of people; the pre-scientific world that we experience in everyday life. Pain management should take the person who is suffering from pain as its starting point. Then, it will become clear that the experience of pain is always characterised by isolation. The social context of the person in pain has fallen apart. The body is left alone. For a dualistic, physiological medical anthropology, the social isolation of the person suffering from pain is considered unimportant. An experience-based medicine however shows that the character of pain alters when the social context of the person in pain alters. The experience of pain should thus be situated in the intersubjective world. Intersubjective contacts situate the body in the life world and as such, they are incompatible with pain. Restoring social contacts abolish isolation and, thus, pain. With Metz, social and physical pain are more or less the same. Experience-based medicine aims at restoring the damaged relation of the person suffering from pain with his/her life world. In doing so, the most important therapeutical instrument is the physician – patient relationship itself. In the 1980s, Metz was a consultant in an outpatient pain clinic. In his contacts with patients suffering from chronic pain, he discussed their life histories. Time after time it showed that the histories of their pains, were also part of the histories of their lives. Pain therapy should therefore explore the life histories of

the patients, not the physiological causes of the pain (Metz, 1997/1998). Other experiences of Metz come from the time he was working in a neuro-surgical clinic. There, it became once more clear to him, that the lives of pain patients had already disintegrated before pain struck them. Almost every patient had difficulties with his/her partner. With Metz, pain and life history are two sides of the same medal.

For the current debate on pain and pain management in the Netherlands, the importance of the works of Buytendijk, Van den Berg, and Metz can hardly be underestimated. Even though important differences in views can be pointed out among them, they did provide a new anthropological orientation in medicine. This anthropological orientation received much interest from the end of the 1940s (Buytendijk) until the end of the 1960s (Metz, Van den Berg). Recently, this orientation is re-emerging in the debates.

3. New interest

In 1979, the leading Dutch medical journal (*Nederlands Tijdschrift voor Geneeskunde*) published a contribution of an outpatient pain clinic physician (Groen, 1979). It is reminiscent of the philosophy of Metz. In the article, the author described his experiences with many patients suffering from chronic pain and their partners. He found that almost all patients dominated their partners before the pain first occurred. Existing marital problems were denied by the vast majority. In various conversations, it appeared that the marriages of the partners were based on 'external' arguments (sense of duty, tradition, reputation). Mutual feelings of love were hardly ever mentioned. The patients were obsessively compulsive, and dominant. The beginning of their pain usually co-incided with a problem in the private, mostly marital, situation; a problem that can be characterised as a defeat in the self-maintenance of the patients. All patients had a history of invasive medical treatment at the time they were referred to the pain clinic. In this history, they had become disappointed in their physicians whom they initially had admired so much. In this disappointment, the one-sidedness of modern high-tech medicine showed itself. The author strongly recommended more research in the areas of psychology, anthropology and communication.

Two years later, another remarkable article was published on pain management and cancer (Crul, 1981). It was a plea for more intensive education in pain management in medical curricula and for a better integration of pain specialists in oncological departments and in hospital care in general.

Furthermore, the author advocated the establishment of hospices as intermediate institutions between the home of the patient and the general hospitals. Also, hospices could enhance pain management directing attention towards the whole person of the patient. To our knowledge, this was the first time that attention to the hospice movement was given in an influential medical journal in the Netherlands.

Two more years later, the book of Sporken (see chapter 1) was published in which it was argued that the growing number of chronic patients necessitated the adaptation of the medical paradigm. The first challenge to medicine should become the acceptance of human finitude. This critique facilitated the rise of more comprehensive perspectives on pain and pain management.

The above publications were at that time not given much attention. In the subsequent years, a public debate on pain and pain management did not take place. Pain management was to remain medicine's stepchild. The innovative ideas that came forth out of the anthropological tradition in medicine were not disseminated. Modern medical ethics, with its interest in autonomy, originated and went hand in hand with a technologically oriented medicine. In 1986, the Dutch Health Council published a report on pain treatment (Dutch Health Council, 1986). It rightly observed a lack of interest in the area of pain treatment. Pain treatment in health facilities was inadequately organised. Anaesthesiologists were only marginally occupied in the area of pain treatment. Chronic benign pain was said to be overtreated while acute pain was undertreated. Because of a lack of interest and a lack of insufficient interdisciplinary co-operation patients suffered unnecessarily from pain. The Council's recommendations to improve pain treatment in the Netherlands were not followed as in 1993 the same bottle necks were observed by State Secretary Simons of the Ministry of *VWS* (Health care, Well-being and Sports), in a letter to Parliament (letter no ZZT/Z, 931288)

Still, at the beginning of the 1990s, (theoretical) interest in alternative perspectives on pain increased, in medical ethics as well as in medical philosophy. For example, various recent publications have interpreted pain as an experience (Ten Have, 1996; Crul, 1996; Morris, 1991). This interpretation, reminiscent of Buytendijk's views, allows for an innovative and broader understanding of pain. To understand what an experience is we can refer to the German philosopher Gadamer. In his *Wahrheit und Methode* (Truth and method) he discerns 'Erfahrung' from 'Erlebnis' ('experience' from 'the subjective impression of an event'; a distinction that is hard to make in English vocabulary) (Gadamer, 1978). *Erlebnis* does not originate in relation to the

world but has its place in consciousness. It refers to itself. On the other hand, *Erfahrung* relates to something or someone from the outside coming up to us. *Erfahrung* originates in relation to someone or something else, acknowledging its integrity or identity. This 'someone' or 'something' comes at us in the form of a question to which we are invited to answer and give meaning to. *Erfahrung* implies a question-answer logic; it takes the form of a conversation. Openness for what/who comes to us is required. After all, a conversation cannot take place if we don't allow this 'other' to speak out for itself. *Erfahrung* always comes up to us as mediated by tradition. It is by *Erfahrung* that we eventually come to know ourselves (Van Tongeren, 1988). Self-knowledge, sometimes seen as the ultimate goal of philosophy and theology, requires that we interpret and sensitise our *Erfahrungen*.

To interpret pain as an experience (*Erfahrung*) is thus not without meaning. It implies that pain is seen as individual (after all, *Erfahrung* takes place in the individual subject) and at the same time as mediated by a tradition. Pain is a culturally shared phenomenon and yet, it throws us radically back to ourselves. Pain is time-bound, place-bound and at the same time irreducibly individual-bound. Pain is at the same time in- and outside ourselves. As such, pain can enhance the understanding we have of ourselves. Pain incites us to provide a meaningful interpretation. The apparent clarity of our daily life is radically put into question by the experience of pain. Pain challenges us and drives us out of our seemingly obvious, self-evident existence. The way we have always known ourselves suddenly becomes endangered when we are in pain. Experiencing pain we are incited to interpret it and thus give meaning to ourselves as being-in-the-world.

The burgeoning understanding of pain since the early 1990s, especially focused on understanding and management of chronic benign pain and cancer pain.

3.1. The debate on chronic benign pain

In 1992, Menges, professor of medical psychology at the Amsterdam Free University, introduced in his book *Over pijn gesproken* (Speaking of pain) new perspectives that have been rather influential (Menges, 1992). The starting point of Menges is that all kinds of pain have a physical, mental and social component. Therefore, even acute pain should be treated interdisciplinary. After all, every chronic pain came up as acute pain. Interdisciplinary pain management from the beginning can prevent acute pain from becoming chronic. For the prevention of the 'chronicisation' of pain, the general practitioner should

be primarily responsible. Interdisciplinarity in the area of pain management prevents medicalisation as well as psychologicalisation of the pain problem. It is not self-evident that chronic benign pain is of a strictly psychological or social nature. Menges criticises the above-mentioned publication of Groen arguing that the prototypical chronic pain patient does not exist. Menges admits that pain can only really be comprehended if it is approached in the context of the total existence of the patient. And it can only be treated if the health professional feels committed to the patient.

Two years before the publication of his book, Menges supervised a thesis on chronic pain management, written by Vrancken (Vrancken, 1990). The author had done qualitative research in 8 pain clinics in academic hospitals. These clinics are, according to Vrancken, the sites where medicine is most radically confronted with the boundaries of its theory and practice. She raises the issue whether, in the light of the complexity of the pain problem, the pain team is able to apply strategies that are different from the dominant ones in medicine. The hypothesis is that on the basis of everyday practice in pain clinics, different concepts can be constructed within different theoretical models. Vrancken distinguishes a dualistic, physiologically oriented model, a behavioural model, a phenomenological model, and a so-called consciousness model. In the dualistic model, the physician does acknowledge the importance of psychological and social aspects but does not involve him/herself in the management of these aspects. The physician focuses on physiological aspects and their causal explanations. The behavioural model intends to change the behaviour of the patient in order to make him or her able to cope better with the pain problem. In this model, the physician is not concerned with the existential suffering of the patient. The phenomenological model underlines the philosophy of Metz and approaches the patient in his or her lifeworld. Its first priority is not to control the pain but to restore the patient's relationship with his or her life world. In the consciousness model, pain management is considered a process to help people reflect on their existence.

The qualitative research of Vrancken shows that, in spite of a variety of theoretical models, medical practice is to a large extent determined by a pragmatic approach (what works?). The discrepancy between theoretical models and everyday practice is called, 'the pain of medicine'. In the final part of her thesis, Vrancken pleads for a practice which is based on the phenomenological together with the consciousness models. These models articulate the underlying suffering of the patient and help the patient reflect on him or herself in his or her existential crisis. Not only are these two models best capable of pain relief for the patient, they can also potentially relieve the 'pain of medicine'.

In 1994, the above mentioned Secretary of Health, Simons, designated four academic hospitals with a regional function to improve the treatment and prevention of the chronic benign pain syndrome. In the year 1997, Crul became the first Dutch professor of pain and pain treatment. Het got his chair at the academic hospital in Nijmegen which is one of the four designated centres. In his inaugural lecture, he demonstrated that pain and pain treatment are still medicine's stepchild (Crul, 1997; 1981). This underestimation of pain can be explained because pain cannot be accommodated in the Cartesian framework through which medicine is determined to a large extent. Crul states that expertise in pain management is insufficient. Inadequately treated acute pain unnecessarily becomes chronic. Pain treatment is hardly given any attention in the medical curricula. Pain treatment in new-borns is largely underestimated because of the mistaken idea that new-borns would not experience any pain. Also post-operative pain is insufficiently treated. The consequence is the formation of a 'pain-memory' which leads to an increased susceptibility to pain which in its turn leads to psychological problems, e.g. anxiety and fear.

In the same year as Crul, Zuurmond also was appointed as professor of anaesthesiology, specifically with regard to pain treatment, at the Amsterdam Free University.

Even though the perspectives of the above publications are divergent, they do reflect a consensus that adequate management of chronic benign pain requires a different approach than the traditional Cartesian, dualistic one. Chronic benign pain leads medicine towards its boundaries like no other disease or symptom. Chronic benign pain will never be adequately manageable within a medical framework but instead necessitates an interdisciplinary approach. But again, medical practice is slow to adopt to this understanding.

3.2. The debate on cancer pain

In the Netherlands, the number of cancer patients will increase due to ageing of the population. Better diagnostic procedures, together with better curative and life prolonging treatments, will increase the life expectancy of cancer patients. Such developments make the issue of quality of life of cancer patients extremely urgent. Pain is a symptom that can severely harm the quality of life of patients.

A 1989 quantitative study delineates the problems with regard to the pain management of hospitalised cancer patients and cancer patients at home, with a prognosis of two months or more (Dorrepaal, 1989). In the clinic (the research was conducted in a clinic specialised in oncology), 45 % of patients suffered from pain. In 54 % of these cases, pain treatment was evaluated as insufficient.

Often, too small amounts of analgesics were administered. In 1989, physicians as well as patients still feared the side effects of analgesics and physicians were reluctant to administer high doses. 49 % of patients coming home from hospital decided to decrease the dose of analgesics. 16 % of the patients at home suffered from pain (patients with complete tumor remission and patients with a life expectancy of two years or more also were included in the research group). About 18 % of the patients to whom analgesics were provided, were advised to take them on an as needed basis. This practice has been criticised in the literature for a long time. In 1963, Saunders already resisted the pattern that patients would have to ask for pain relief (Clark and Seymour, 1999). Dorrepaal found also that pain management was unsatisfactory in 47 % of the ambulant patients. Exchange of information between the medical specialist and the general practitioner was also evaluated as insufficient. Many patients did not even have contact with their general practitioners and only communicated with their medical specialists. The latter did not inform the patient's general practitioner. Dorrepaal concludes on the one hand that specialists should exchange more information with the general practitioners and that on the other hand, the general practitioners and patients should take more initiatives to communicate with each other. Also the psychosocial consequences of cancer pain should be more fully acknowledged.

Since 1989, when this thesis was published, many things have changed (Van den Toorn, 2000). Prejudices with regard to the use of analgesics have diminished, at least on the side of the professional medical community. Actions to improve the communication between primary and secondary health care are currently under research. To facilitate the co-ordination of cancer pain management, the so-called integral cancer centres play an important role. Expert consulting teams provide consultations in the home of the patient or in the hospital. Many hospitals have developed in- and outpatient initiatives to improve pain management. New technological applications in the house of the patient have received wide recognition (Van Boxtel, 2000). When the four centres for treatment and prevention of chronic pain were established in 1994, this was done because of insufficiencies in the treatment of benign pain whereas with regard to the treatment of cancer pain fewer problems were noted. According to recent estimations, 80 % of all cancer pain can be controlled (Crul, 1998).

The growing interest in palliative care has led to increasing interest in psychosocial and spiritual aspects of pain management. It can be argued that the inclusion of these non-physiological aspects of pain in the total pain concept is not so much a widening of the Cartesian understanding of pain, but rather a

different understanding of pain. The concept of total pain, contrary to the Cartesian concept of pain, interprets pain in the context of the life world of the patient. The concept of total pain thus challenges the traditional biomedical understanding of pain, since it locates pain in the larger perspective of the human life.

4. Perspectives for the future

Interestingly, and perhaps paradoxical to what has been said above, it has also been argued that the concept of total pain still contains fundamental traits of the Cartesian concept of pain. According to Lanceley, "... the division of pain into components and categories of physical, social, mental or emotional pain, as if each were on a different plane of experience, is stark evidence of the intractability of Cartesian thinking amongst even the most sophisticated of clinicians'' (Lanceley, 1995, p. 154). Pain in cancer care is said to be still approached as an obstacle that should be eliminated in order to allow for a meaningful dying process. Not much attention is given to the meaning of pain for the patient. Palliative care challenges the traditional organic model as it locates pain in a larger perspective but basically, the biomedical model is maintained. Also in palliative care, pain management seems synonymous with pain treatment. Apparently, if one follows Lanceley, palliative care stands midway between a traditional dualistic concept of pain and a burgeoning post-modern meaning-centred concept of pain. It is possible to argue that the holistic concept of pain in palliative care is in need for a radicalisation, in the direction of a post-modern understanding of pain. According to the latter understanding, pain management should not exclusively be interested in pain control. Sometimes the pain of a particular patient does not ask for an activistic approach, but for passively allowing the patient to be the guide. This post-modern concept in which the meaning of pain is recognised may in the future well be adopted by caregivers in palliative care.

According to Lanceley, it is imperative to listen closely to the narratives of patients. These narratives may reveal wider perspectives on pain that currently are still underneath the surface, also in cancer care and palliative care. Then, medical pain treatment occurs as one possible perspective on pain. The multi-dimensionality of pain will be revealed. The mystery of pain will not be solved but acknowledged. Refraining from pain treatment will occur as an option to be considered. For many patients this will enhance the understanding of

themselves. It will enable them, even in terminal illness, to develop themselves further, giving meaning to their pain and to their lives.

If we listen very closely to the narratives of chronic pain-patients we can discern a new non-dualistic vision of pain. Most patients objectify their pain as something outside themselves as illustrated in the phrase: 'It hurts'. But some patients, often after having had a period of objectifying their pain, eventually come to see their pain in identification with their own selves (Lanceley, 1995). Narrating their experience in vivid symbols and images, they, consciously or unconsciously, attribute meaning to their pain. Narratives shape the self-understanding of patients. They are the mediation through which patients understand their 'being-in-the-world'. Meaningful experience cannot do without narratives. Moreover, narratives are the condition of possibility for meaningful experience. Jackson cites a patient: "I believe the snake is me... My God, I can talk to it... I was afraid of it... But the pain is me" (Jackson, 1994, p. 205). Taking these narratives serious, one can find indications for the need of a more meaning-centred, instead of a biomedical, approach to pain management.

However, as stated in the introduction, pain seems an experience too diffuse, too many-sided as to encapsulate it into a cultural framework or into one meta-narrative. The post-modern era can allow pain to "serve multiple purposes and hold multiple meanings beyond its basic function as a signal of tissue damage" (Morris, 1991, p. 279). The biomedical model will remain one among many explanatory models. But apart from this model, pain can be given various existential, religious, social, psychological, literary and poetical meanings. None of them will eventually exhaust the experience of pain but together they can shed light on the many meanings pain can entail. Therefore, hermeneutical research, re-introducing unheard voices and discovering hidden areas in which pain is not stripped of its meaning, is paramount.

Conclusion

There is much to be done to improve our understanding of pain and pain treatment. But it can be argued that since the last decade more and more attention has been paid to this area. Expertise in pain management will further develop. Through consultation and education, expertise will be disseminated. In the literature there is nowadays consensus that the Cartesian biomedical paradigm has failed.

In searching for alternatives, the phenomenological tradition has not lost its relevance. After all, the 'pain of medicine' has not been relieved yet. Still, a discrepancy exists between ethical and philosophical theories and medical

practice (Vrancken, 1990). In medical practice, pain continues to occur with images of battle, as pointed out by Buytendijk. Medical treatment is regarded as the primary means of pain management. Interdisciplinarity is often only underlined when medical treatment fails, instead of acknowledging its importance from the beginning of the process as emphasised by Menges. Even the concept of total pain is also, and in spite of its intentions, illustrative of the Cartesian paradigm, as it distinguishes between four relatively separate realms of care.

If that is so, new understandings of pain, that have hardly been articulated yet, should be proposed; understandings that allow for other ways of dealing with pain than only medical intervention (justified as that may be under many circumstances). Narrative approaches have been proposed which certainly allow for meaning giving and receiving. Perhaps, research in ways of dealing with pain in the pre-Enlightenment era can be fruitful in revitalising old and forgotten perspectives. Innovative theoretical research (for example Morris) has shown how in our society pain has more meanings, even positive meanings, than may appear at first sight.

Relief of the 'pain of medicine' seems one of the major challenges for future medicine. Acknowledging interdisciplinarity and potential meanings of pain in theory however, is something different from changing everyday practice according to these points of view. Even though much progress has been made recently, medical practice is still slow to adopt to the new challenges lying ahead. A continuation of the debates on possible understandings of pain is therefore imperative as many innovative perspectives have already been proposed during the last few decades. Also in the future, pain will remain a mystery but acknowledging this mysterious character of pain will prevent medicine from hubris. Pain and the possibilities and impossibilities of pain treatment have confronted medicine with its boundaries. Relief of the 'pain of medicine' implies an acknowledgement of these boundaries.

Note

* The first article is a philosophical and theological critique on the medicalisation of pain. In contrast to this chapter, it does not focus on the phenomenological tradition. The second article is an analysis of the Dutch debate on pain and pain treatment and a description of the organisation of pain management in the Netherlands. This chapter pays less attention to the organisational aspects. The chapter can be considered a critique on the medicalisation of pain and pain treatment, based on the work of Dutch philosophers and physicians. It contains excerpts from both articles.

CHAPTER 6

THE NOTIONS OF RESTRAINT

AUTHENTICITY AND HOPE

A slightly modified version of this chapter was published as*:
Janssens MJPA, Zylicz Z, ten Have HAMJ, Articulating the concept of palliative care. Philosophical and theological perspectives. *Journal of Palliative Care* 1999; 15(2): 38-44.

THE NOTIONS OF RESTRAINT, AUTHENTICITY AND HOPE

Introduction

In the *Oxford Textbook of Palliative Medicine* palliative medicine is defined as "the study and management of patients with active, progressive, far-advanced disease for whom the prognosis is limited and the focus of care is quality of life" (Doyle, Hanks and MacDonald, 1996, p. 3). Defining palliative care adequately is not easy; many conceptual distinctions are made among, for example, palliative care, palliative medicine, hospice care, terminal care, and palliative care services. One useful way to examine the concept of palliative care is to consider it as a philosophy of care or an approach (Robbins, 1998). Both for people who are dying and for those who look after them, our understanding of palliative care can be enriched by identifying and examining the notions that play an important role in this philosophy of care.

This chapter examines three notions that, though not absent in the debates on palliative care, have not been given the attention they deserve. By situating these notions in the philosophical and theological traditions from which they originate, we can enhance our understanding of palliative care.

Palliative care is total care. The person of the patient is at the centre of care. This means that not only the medical but also the psychosocial and spiritual needs and wishes of the patient must be addressed during the period of care (Saunders, 1967; Twycross, 1996).

In this chapter, the distinctions between the medical, psychosocial and spiritual realms of palliative care will be examined. Inherent to the medical realm is the notion of restraint, derived from the Hippocratic tradition. Inherent to the psychosocial realm is the notion of authenticity which is specified within the philosophical tradition of existentialism, and to the spiritual realm the notion of hope, a central virtue in the Christian tradition. the notions will elaborated on within the context of a paradigm case from hospice practice.

Case report

A woman of 58 years was suffering from a small-cell lung carcinoma. When the patient was informed of her diagnosis, the first thing she said to the oncologist was that, when her suffering became unbearable, she would want to have euthanasia, which is under conditions tolerated in the Netherlands.

In the sixth month after the diagnosis, she contacted a hospice physician. She asked for information about hospice care in order to make arrangements for the future. She was told that euthanasia was not performed in the hospice but that, independent of her decision, the carers would never abandon her. If she still preferred euthanasia, in spite of all efforts of the interdisciplinary team, she would be discharged to a hospital where euthanasia would be provided. Her treatment program at the time was aimed at a cure and, though she knew that chances for a cure were limited (6 % long term survival).

The woman, a lawyer, had been extremely busy throughout her life. Her marriage had failed and she was divorced. She had two daughters, one of whom lived with her ex-husband and the other with her. However, her relationship with both her children was very detached. The sisters had not seen each other for years.

Thirteen months after the diagnosis, the woman was admitted to a university hospital with pain in her back. Metastases in the brain and spinal column were diagnosed. A course of radiotherapy and chemotherapy aimed at life prolongation and the palliation of symptoms were initiated.

Sixteen months after the diagnosis, the woman decided to discontinue chemotherapy and, at her request, she was admitted to the hospice. At the time she was using opioids and suffering from dyspnea, constipation, and nausea. It appeared that the dose of opioids was far too high. Her dose was decreased and her symptoms were alleviated. Corticosteroids were prescribed to alleviate the headache and nausea.

Because she was then paraplegic, she had to let others take care of her. This made her very unhappy. She felt guilty toward the caregiving team and she became very demanding and unreasonable toward her children. Her caregivers tried repeatedly to reassure her that they enjoyed looking after her and that she had no reason to feel guilty. During this period she did not talk about dying and she refused to meet the pastoral worker.

One morning, the hospice physician entered her room and, like a bolt from the blue, she started to cry. She said that she was afraid to die and that she felt guilty about her children, whom she had never been able to take care of. She also said that she was afraid her children would never see each other again after

her funeral. From that time on, many things changed. She talked about her oncoming death to her children as well as to the pastoral worker. The children stopped avoiding each other. Together with them, she arranged her funeral service. She started to enjoy the high standard of care she was receiving. She even stopped quarrelling on the phone with former colleagues at work. Her relations with the people around her improved greatly.

Nineteen months after her diagnosis, she re-established contact with her sister, who lived in India. The patient then felt reassured that she had said and done all the things she needed to. Apart from fatigue, she did not suffer from her symptoms. She had enjoyed her months in the hospice and had accepted her fate. During one of her last discussions with the hospice physician, she repeated her request for euthanasia. She wanted to die. She was afraid that the dying process would be endless and that she would deteriorate slowly. The hospice physician proposed an alternative – that she discontinue the corticosteroids. She knew that death would soon follow. She said that she needed a day to consider this option. She phoned a school friend, a rheumatologist, who confirmed the rationality of this option.

She agreed to the proposal and felt relieved. She even asked out loud why so few people chose to die this way. Four days after the withdrawal of the corticosteroids, she died peacefully in the presence of her daughters.

1. The medical realm and the notion of restraint

Coming up with a simple definition of the notion of restraint is problematic; nonetheless, two essential components of such a definition can be formulated. First, medical restraint implies the acknowledgement of the boundaries of medicine. Second, medicine co-exists with other, equally important elements in enhancing the well-being of patients.

In the Hippocratic tradition, restraint was once the physician's virtue. Medicine was understood to obey the laws of nature, not by passively accepting the existence of diseases but by acknowledging that, first and foremost, the body attempts to bring about its own recovery. Medicine can influence the body's mechanisms only to a certain extent. In the Hippocratic tradition, the physician is the servant of nature (Zwart, 1996a; Zwart, 1996b) and medicine aims at the recovery of the original natural state (Pellegrino and Thomasma, 1981). The ethical rule that pervaded Hippocratic medicine was 'in dubio abstine' (when in doubt, do not intervene).

Modern medicine seems to have forgotten its Hippocratic roots. It has turned away from nature, pretending to be able to control and overrule it. 'In dubio abstine' seems to have become: 'when in doubt, act' (Ten Have and Kimsma, 1987). The expansion of medical technology has done much good, but the technology can also lead to suffering. Patients with incurable illnesses, though they may be surrounded by medical personnel, can be neglected while the professionals focus on cures and life prolongation. Such patients experience personally the limits of medicine - its inability to control nature. Their situations reveal the urgent need for a modification of medicine.

Elements of the Hippocratic tradition can be found in palliative care, where the proverb 'let nature take its course' is often heard. In palliative care, after the curative phase, nothing is done to hasten or postpone death. Palliative care focuses on the quality of life; quantity of life is not a criterion in decision making. In the progressive disease process of the patient, the criteria for medical decisions gradually change until no further attempts are made to postpone death. Often, the patient and the physician decide together to stop aiming for life prolongation, even when another treatment could add months to a patient's life. Such was the case for the woman described above.

As finding a cure and life prolongation become less and less important, the medical realm becomes an integral part of the psychosocial and spiritual realms. Adequate pain and symptom control aim at providing as much comfort as possible to the dying. Psychosocial and spiritual care have the same aim. The boundaries between these three realms are not clear-cut.

When life prolongation is no longer feasible, many varieties of medical treatment become futile. For the woman described in the case report, restraint was considered mainly for medical reasons related to the adverse effects of the high dose of opioids she was receiving. However, often the final criterion determining medical futility relates to the wishes and needs of the patient. Apart from a lack of effect related to physiology, a lack of benefit as to the personal needs and wishes of the patient is an important criterion of futility (Smith II, 1995). Can the patient enjoy his or her remaining life? Is the patient ready to die? Is everything said and done with regard to relatives? Does the patient accept death? In the light of these questions, it is hard to set guidelines for futility of medical treatment in palliative care.

The corticosteroids were effective for the patient described because they alleviated her symptoms and prolonged her life. However, the corticosteroids became non-beneficial from the woman's perspective after she went through a change of attitude. Her case clearly showed that medical treatment is only one

aspect of palliative care and that it is intrinsically connected with psychological, social and spiritual care.

In palliative care, more than in curative care, the adequacy of medical treatment depends on the needs and wishes of the individual patient. A clear somatic indication for medical decision making is often absent. Medical decision making in palliative care is part of a multi-dimensional process relating to unique individuals. A change in the social relationships, psychological moods, or spiritual attitudes of patients can lead to changes in medical decisions. The notion of restraint illuminates the interrelationship of the medical and the psychosocial and spiritual realms. Psychosocial and spiritual aspects often overrule the strictly medical point of view.

Medical restraint should not be regarded as a defeat. Restraint opens up new possibilities. Patients may finally come to rest after months of mutilating invasive treatments. Withdrawing curative or life-prolonging treatment and accepting the boundaries of medicine enables the physician to follow the patient on his or her way towards death. A kind of passivity on the part of the physician can be seen as a way for her or him to be sensitive and responsive to the patient as a person (Desmet, 1996). Medical restraint thus points the way to the psychosocial realm.

2. The psychosocial realm and the notion of authenticity

It has often been argued that the principle of autonomy is central in palliative care (Veatch and Spicer, 1992). However, the principle of autonomy is ambiguous.

Its origins go back to the age of the Enlightenment. It was the German philosopher Kant who first introduced autonomy into the philosophy of the Enlightenment. But for modern medical ethics, the views of the English philosopher Mill are regarded as more important (Vedder, 1995). With Kant, ethics is impossible if one does not presume that human beings are able to relate to themselves. Autonomy, according to Kant, is the capacity of human beings to impose the moral law on themselves. Autonomous human beings are no longer led by 'foreign' heteronomous forces (Kant, 1978). Rather, they set their own moral law and have learnt to make choices for themselves. With Kant, autonomy is the capacity for self-legislation. John Stuart Mill did not directly address the concept of autonomy, but his writings have been extremely influential for 20th-century philosophy. He stressed that as long as no harm to others is done, the right to independence of the individual is absolute (Mill, 1975). As long as no

others are harmed, it is illegitimate to interfere with individual actions. The individual has sovereignty over himself.

Important traces of the philosophy of Mill can be found in modern medical ethics. The rise of medical technology and the physician's power in the late 1960s led to calls for safeguarding the autonomy of patients (Engelhardt, 1991; Zwart, 1995). In this ethical discourse, patient autonomy was a backbone of a libertarian ethics. Autonomy and self-determination became synonymous. This discourse is at odds with palliative care practice because it is based on mistrust between the patient and the physician. In the end, the patient stands alone with his or her self-determination (Welie, 1998).

Recently, a broader concept of autonomy has been developed. It includes recognition of human vulnerability, dependency, and fragility. Using these concepts, an ethics of care that is concordant with the concept of palliative care can be constructed (Manschot, 1994). However, in this chapter another approach is taken, for two reasons. First, autonomy is rooted in a libertarian tradition that is incompatible with palliative care. And second, since the rise of modern medical ethics it has been part of a principlist moral framework that primarily served to deduce moral guidelines instead of enhancing our understanding of moral practices (Beauchamp and Childress, 1994). Therefore, it would be more appropriate to approach palliative care with the help of another notion. The notion of authenticity is suggested here since it can provide us with a better understanding of palliative care practice than the ambiguous principle of autonomy.

According to Charles Taylor, authenticity is a child of the Romantic period (Taylor, 1992). He has suggested that the initial development of the concept was situated in the "... eighteenth-century notion that human beings were endowed with a moral sense, an intuitive feeling of what is right and wrong" (Taylor, 1992, p. 25-26). In order to be virtuous, we have to look deep inside ourselves. We have to learn to be in touch with ourselves, in touch with our own originality. This idea was often overlooked by the rational philosophers of the Enlightenment.

Concern about the lack of 'inwardness' of society was also expressed by the predecessor of existentialist philosophy, Søren Kierkegaard. For him, passion had disappeared from life and, in consequence, existence had become fearsome. We all stand alone, confronted by an absurd, irrational world. Truth does not exist in itself but depends on what is true for the person involved. It is the subject who will have to shape existence through choice. And, in the process of shaping existence, certain stages can be distinguished. In other words, even though choices should be individual ('authentic') in character, the values from

which one should choose are pre-existent. Kierkegaard distinguished the esthetical stage (in which one avoids to make existential choice), the ethical stage (in which one realises one's responsibility for oneself and others) and the religious stage (of which the acceptance of Christ as God is the highest form). Despair pervades Kierkegaard's philosophy but, at the same time, there is a concern about the irreducible singularity of all human beings. Human beings are driven to make the choices that best fit their own existence. Such human beings can rightly be called authentic.

The philosophy of the French existentialist Jean-Paul Sartre can be understood in the light of Kierkegaard. According to Sartre (and contrary to Kierkegaard), we live in a world that has no meaning apart from the meaning we give to it through choice (Sartre, 1944). "In choosing ways of life, we colour the world with values" (Árnason, 1994, p. 229). People who think that the world in itself contains meaning are inauthentic, living in 'bad faith' (*mauvaise foi*) as they try to escape from the anguish that pervades existence. Authenticity relates to the morality of the subject. Morality is created by the individual through choice and by commitment to choice. The philosophy of Sartre seems problematic because morality cannot be found apart from the individual. In other words, with Sartre, freedom seems to be the same as arbitrariness. However, Sartre's elaborations on choice and commitment are meaningful in this context.

Apart from the element of choice, the notion of authenticity contains another important element to which the German philosopher Heidegger (who did not want to be called existentialist) drew attention (Heidegger, 1986). For him, human beings are radically contingent, vulnerable, and fragile. When they are born, they are thrown into an historical situation that they did not choose. Contingent factors such as bodyliness, past, culture, and traditions shape our identity, for better or for worse. Authentic human beings are those able to endure the tension between the freedom to make choices on the one hand and their contingency, fragility, and dependency on the other hand. For example, they cannot always avoid illness (because of their fragility) but they can choose how to relate to illness. An authentic decision is one in concordance with the original identity of the subject as it has evolved in the past, as it is in the present and as it will shape itself in the future through the choices it makes.

There are many differences between the authors mentioned above and in elaborating on authenticity as a central notion in palliative care we cannot entirely avoid some eclecticism. Two ideas are fundamental: First, a person's choices are put into the perspective of a person's unique personality. Second, apart from the element of choice, authenticity also takes our common fragility, contingency, and dependency on others into account (Welie, 1994).

Authenticity means being at one with oneself, despite all (potential) suffering. It means the integration of one's suffering with one's existence (Manschot, 1994). But a person cannot achieve this on his or her own when at the end of life. Palliative care is directed toward the sustainment and fostering of a patient's authenticity through the realisation that the caregivers and the patient share the condition of dependency and vulnerability as well as the ability to make free and authentic choices. An acknowledgement that these traits are common to all people can open the way for caregivers to provide compassionate care for the most fragile and dependent members of our society. Our solidarity with the dying is symbolic of the solidarity of our society in general. The notion of authenticity situates the individual in the context of a community. In some ways, when we care for the dying we are caring for the society to which we belong. Authenticity can be taken as a communitarian concept involving the idea of compassionate care.

The dying are no less authentic than the healthy. Exactly because we can relate to our radical dependency and to our fragility the dying can be as authentic (or inauthentic) as anyone else. First and foremost, the dying are fellow human beings. They experience the *condition humaine* as anyone else. Only after having realised this is compassionate care possible. Compassionate care can be called authentic care because it is directed toward the fostering of a person's authenticity. Everyone surrounding the patient, from the physician to the secretary, has a role to play in fostering the dying patient's authenticity.

Let us consider the woman described in the case report. The first month of her stay in the hospice can be described in terms of autonomy. She wanted to be in control of her own death and did not accept the compassionate care of the team and her children. At one point, however, she came to a realisation. After this, her defensiveness disappeared and she began to accept her dependency on others. The woman opened up to her caregivers. At meetings of hospice workers, her caregivers expressed astonishment at the woman's ability to change and that she could be so at one with herself.

Many physicians in the Netherlands would have acted on this woman's choice to have euthanasia. Her situation certainly fulfilled the conditions under which euthanasia is tolerated. The patient was a competent woman in the terminal phase of her disease. In retrospect, however, it may be appropriate to question whether her choice was authentic (Zylicz and Janssens, 1998). From her reaction to the proposal of the hospice physician it appeared that deep in her heart she was afraid of being put to death. She wanted to die but she did not want to be killed.

For our understanding of palliative care, authenticity is a more adequate notion than is autonomy. Authenticity encompasses the notions of dependency and fragility while leading to the recognition of solidarity, compassion, and love. It also encompasses the notion of freedom of choice and points to the respect for the personal needs and wishes of the dying.

The notion of authenticity can clarify dimensions of psychosocial care. However, authenticity can hardly encompass spiritual care. The philosophical tradition of existentialism stated that 'existence' is all that is real. Only in existence, only in the fact that something 'is', truth can be found. Without existence there is absolutely nothing. The realisation of this foundational idea of existentialism clearly makes life in the face of death absurd and fearsome. Even in Kierkegaard's philosophy, religious faith was only conceivable as the endurance of meaninglessness. It takes an unexplainable 'leap of faith' to become religious. Furthermore, faith, according to Kierkegaard, entailed little more than a personal dialogue with God. But if that is so, existentialism eventually fails because authenticity, together with the notions of freedom, dependency and solidarity looses its meaning in the face of existential meaninglessness, absurdity and fear. This is why the notion of authenticity should be paired with an eschatology that addresses questions on the meaning of life.

3. The spiritual realm and the notion of hope

Perhaps, instead of spirituality, eschatology is a more adequate term to address the realm of spirituality. Eschatology refers to the things of ultimate importance, to what human life is in the end all about. Whereas it used to refer to the afterlife, modern theology stresses the importance of the image of the afterlife for life on earth. Heaven is not so much something we wait for when we die as it is a worthwhile goal to strive for here and now. Real heaven is heaven on earth. That is what we finally hope for. In considering hope as a notion that can enhance our understanding of palliative care we can connect with modern theology within which eschatology plays a crucial, foundational role.

Mortality makes eschatology possible. Because we die eschatological questions urge themselves upon us. Whether we like it or not, implicitly or explicitly, we have to answer questions relating to the meaning of life, exactly because we all live in the face of death. Death forces us to give a final meaning to life and to transcend the apparent absurdity and meaninglessness of life in the face of death. The ultimate meaning we give to life provides us with hope. Hope

is thus an existential category. Without hope we cannot live. For Christians this existential hope, one of the three gifts of grace attributed to the Holy Spirit, relates to God's kingdom. In it humans find their fulfilment. God's kingdom is already present because of the resurrection of Jesus Christ, though it has not yet reached its fulfilment. Even Kant, the rational philosopher of the Enlightenment, states that humans as a moral species strive for a fulfilment that cannot be fully achieved in this world (Kant, 1956). According to him, the 'unimaginable' fulfilment must be considered in order to live in the 'imaginable' unfulfilled present.

If hope is an existential category, it can never be completely destroyed by suffering, disaster, injustice, or violence. Rather, hope resists suffering. Hope liberates (Moltmann, 1966). Dying patients who are suffering from the situation they find themselves in and their relatives who face bereavement cannot live without hope, no matter how small or how deeply hidden it is. Absolute hopelessness, if it exists at all, is in a way death. Often, loving care from friends and relatives can renew a patient's hope. And compassionate care by professionals should be aimed at sustaining and bolstering a patient's hope. The careful communication of the truth with regard to a patient's condition is a better basis for sustaining hope than is the fostering of illusions (Kodish and Post, 1995).

The seeming contrast between suffering and hope is irrefutably counterbalanced by many dying patients, who reveal that severe pain, of any kind, does not extinguish hope. Consider our patient: Even though statistically the chances of long-term survival with small cell lung cancer are 6 %, the woman hoped that she would be cured during the first year of her disease process. She stopped smoking and did exactly what the doctors told her to do. She began smoking again when she heard that her disease was progressing. She opted for palliative chemotherapy and radiotherapy to live with an acceptable quality of life for another couple of months. During that time, she regularly went to work and finished what she had to do. Then, the time came when palliative chemotherapy had to be discontinued and she was admitted to the hospice. To the caregiving team she seemed detached. She was afraid that her brain metastasis would drive her insane, that she would suffocate and die an undignified death. However, she did hope to live long enough to see once again her sister, who lived in India.

From the day she showed her grief to the hospice physician, she grew more and more 'authentic'. She was no longer afraid to die. Her request for euthanasia could be seen as a paradoxical sign of fear of death. When it was decided that the corticosteroids would be discontinued, she felt relieved. Her daughters managed well and she died in dignity.

During the course of her disease, this woman's hope varied in object. Time after time she shifted her bounds. Initially, when there was still a small possibility for a cure, the main object of her hope was survival. When it became clear that she had only a couple of months to live, her hope was founded on the quality of remaining life. By the time life-prolonging treatment was withdrawn, she felt fear but still had hope, hope for a dignified death and a visit from her sister. During the last weeks of her life she expressed concern about her daughters; she hoped they would manage well together. Undoubtedly, this woman must have had periods when hope appeared to be absent. Still, time after time she was able to regain hope and enjoy her life. In this respect, the care she received from her children, friends and from the caregiving team was of paramount importance.

The fostering of patients' and relatives' hope can be seen as central to palliative care because hope is conditional to a life worth living.

Conclusion

It is suggested that medical restraint, authenticity, and hope are notions that can enhance our understanding of palliative care. Their meaning has been examined in the context of different philosophical and theological traditions from which they originated and have related them to the story of a patient.

The notion of restraint emphasises the acknowledgement of the boundaries of medicine. In the medical realm of palliative care, the disease process is no longer treated and the patient is allowed to die. Furthermore, restraint leads to recognition of the multidimensionality of palliative care. The medical realm cannot be considered separately from the psychosocial and spiritual realms of palliative care. Medical restraint can also be understood as a way of being susceptible and responsive to the patient.

The notion of authenticity is proposed as one that is more likely to provide a meaningful perspective on palliative care than does the principle of autonomy. Within the notion of authenticity patients' choices are understood not as ad hoc decisions that have to be met but as choices related to personality and character. Furthermore, this notion takes human fragility and dependency into account. Those who care for the dying should presume that dying is part of life. The dying are fellow human beings. They should be seen as equals, as subjects with a need and a right for the best of care. If we deny them this right, we deny a part of ourselves, as we are as vulnerable and fragile as the dying and equally

inclined to make choices appropriate to our personalities. Through palliative care, the authenticity of the dying should be fostered.

The notion of authenticity is situated within the tradition of existentialism and it is argued that existentialism eventually fails in providing the foundations for authenticity. Authenticity loses its meaning in the face of existential absurdity and fear. Therefore, authenticity should be paired with an eschatology in which the notion of hope is foundational. Hope is an existential category without which we cannot live. Even severe suffering cannot extinguish hope. Many patients with incurable illnesses and their relatives redirect the object of their hope time after time. Hope is one condition of a life worth living. Therefore, it should be fostered through adequate palliative care.

These three notions should play a more important role in the debates on palliative care. They can provide a means by which those working in palliative care can articulate and sensitise their experiences. The notion of medical restraint may be relevant to the medical profession in general. And the notions of authenticity and hope may be interpreted more generally as virtues that hold significance for everyone. However, in the context of the care for the dying, there is a particular urgency in understanding them. The dying are members of our society. They are just like everyone else, except that they are about to leave us. A society that withholds the best possible care for its departing members is in danger of losing its cohesion (note that the Latin roots of the word 'society' refer to 'fellowship' and 'union'). The care we give to the dying is therefore not only due care, it is also an illustration of the cohesion and morality of our society.

Note

* Modifications in comparison to the published article:
- The title has been changed.
- The notion of authenticity is analysed here in paragraph 2. In the article, a paragraph was added whereas the text has remained the same.

CHAPTER 7

HOSPICE AND EUTHANASIA IN THE NETHERLANDS

AN ETHICAL POINT OF VIEW

A modified version of this chapter was published as*:
Janssens MJPA, ten Have HAMJ, Zylicz Z, Hospice and euthanasia in the Netherlands. An ethical point of view. *Journal of Medical Ethics* 1999; 25: 408-412.

HOSPICE AND EUTHANASIA IN THE NETHERLANDS

AN ETHICAL POINT OF VIEW

Introduction

As part of a research project on palliative care ethics, a two-months' participant observation has been made of terminal care practice in the Hospice Rozenheuvel in Rozendaal near the city of Arnhem in the Netherlands. In contrast to theoretical analysis, this study provided opportunities to experience the intrinsic connectedness of moral issues with everyday hospice practice (Ten Have, 1994; Welie, 1994).

In this chapter, first the organisational context of hospice care in the Netherlands will be briefly presented with a specific focus on the Hospice Rozenheuvel. Subsequently, several complex moral problems directly and indirectly related to the problem of euthanasia which arose in hospice practice during the observation period will be discussed by means of four case reports.

1. Hospice care in the Netherlands

In April 1996, the 'Network Palliative care for Terminal patients in the Netherlands' (*Netwerk Palliatieve zorg voor Terminale patiënten Nederland, NPTN*) was founded. It is a network organisation with the majority of professional palliative care organisations as members. According to the data of this network there were in the Netherlands in 1998, 16 hospices of which 2 were in the process of establishment (NPTN, 1997). These 16 hospices vary to a great extent in professionality; 7 of them are member of the Netherlands Hospice Movement (Nederlandse Hospice Beweging, NHB) which is a foundation that unites local voluntary 'hospice-groups' which care for patients at home. If care at home is no longer possible, patients can be taken care of in a so-called 'almost-at-home-home' (bijna thuis huis). This is a house with a personal atmosphere; it functions as a substitute residence where the patient can be as 'home' as possible. The general practitioner of the patient remains responsible and the family is much involved in the care for the patient. Only volunteers are working in these almost-at-home-homes. The Netherlands Hospice Movement requires that the houses are not based on a religious conviction. It does not take a stand to euthanasia which is deemed the responsibility of the general practitioner together with the patient. Obviously,

from these 'almost-at-home-homes' there is no formal information exchange to the formal health care system (except for the visits of the general practitioners) but the co-operation with the home care services of the region is close. The financial sources are private donations. All houses have 3 beds (total of 21). The first almost-at-home-home was founded in 1986 in the village of Nieuwkoop.

Apart from these hospices associated with the NHB, there are, according to the data of 1998, 5 more 'low care hospices'. These hospices have a Christian foundation and euthanasia cannot be provided inside the hospice. They are financed by churches and religious congregations and by private gifts. Their aims resemble those of the almost-at-home-homes. The patients do not have to be Christians themselves. These five hospices have 27 beds all together. They have all been established in the late 1990's.

In 1999, there were 4 professional 'high care hospices' in the Netherlands. These hospices have a physician specialised in palliative care (some physicians followed specialisation programmes in the UK). 3 out of these 4 hospices provide regular consultations to general practitioners taking care of the patients at home. Most of their patients suffer from pain or other symptoms and are in need of specialist palliative care although temporary relief of the home care situation can also be a reason for admission. Even though the hospice physicians do visit the houses of the patients for intake, the hospices themselves do not provide home care. For their finances, the hospices rely to a great extent on private foundations and gifts. All hospices provide family and bereavement support. All professional hospices are Christian but patients are never refused because of their religious views. These hospices have 29 beds all together. The first of the four hospices was founded in 1991 in Vleuten near the city of Utrecht. Of these hospices, the Hospice Rozenheuvel is internationally known, not only because of the international publications of its physician but also because of its educational activities which attract a world-wide audience. This hospice was established in 1994 and is financed by the Salvation Army. Sometimes one can read in the literature that the Netherlands has only one hospice, founded in 1994 (e.g. van Schaik, 1994). Even though this is incorrect and does not do justice to the other hospices, it reflects the particular status of the Hospice Rozenheuvel. Rozenheuvel comes close to the model of the British hospices. It is an in-patient hospice with nine beds. The hospice physician also offers advice to general practitioners who take care of patients at home and to internists working in a nearby hospital. Apart from in- and outpatient care, the hospice also co-ordinates international educational and research activities. The hospice is affiliated with several foreign palliative care associations. Of the other two hospices, one, the hospice Calando, was founded in

1998 in Dirksland, south of Rotterdam, and one, the hospice Kuria, was founded in 1992 in Amsterdam.

Apart from these 16 hospices, one children's hospice was founded in 1997. It provides place for 8 children who are cared for by specialist nurses, volunteers and an educationalist.

Although currently many low-care hospices are originating, the climate for a further institutionalisation of high-care hospices is negative. It is argued that the Netherlands is in need of a small number of highly specialised professional hospices. These would primarily serve as education and consultation centres for nurses, general practitioners and medical specialists (Zylicz, 1994). Thus, without becoming a medical specialism, specialists in palliative care would be brought forth by education in these hospice centres. These specialists would provide consultations to their colleagues in hospitals or primary care-practice. But the majority of physicians and policy makers hold that, since the quality of Dutch health care is good and since the academic centres have good potentials to provide educational activities and co-ordinate further research, there is no need to establish separate institutions (see chapter 4).

It is important to realise that all Dutch high-care hospices, including the hospice Rozenheuvel, base themselves on a Christian world view and therefore do not consider euthanasia as an option in palliative care. In the context of a country in which the practice of euthanasia has been accepted by the majority of the population (e.g. Dutch Parliament, 1997) they can be seen as a critical minority. All hospices want to show that through compassionate palliative care, many (not all) euthanasia requests can be prevented or taken away. The maxim that the patient's death should neither be intentionally hastened nor uncritically postponed is pervasive for hospice practice. In this contribution, an account is given of a participant observation in the Hospice Rozenheuvel, in the village of Rozendaal. It will be indicated that, even though the maxim is morally crucial for hospice practice, its application to everyday practice is not easy and sometimes goes hand in hand with mixed, ambivalent emotions.

2. Moral decisions at the end of life in a Dutch hospice

In this section, various moral decisions concerning the above mentioned maxim (i.e. not intentionally to hasten, nor uncritically to postpone a patient's death) will be analysed with the help of four case reports. The case reports are helpful because they indicate how the maxim is integrated in everyday hospice practice. Often, the application of this maxim is problematic and in need of a critical

analysis. Sometimes, the needs and wishes of the patient are ambiguous. Also, differences of opinion between the patient and his/her loved ones can be difficult to manage. Ample discussion with the patients and their families cannot always neutralise ambivalent emotions for the clinical team.

Case 1: Terminal sedation

A woman of 61 years old suffers from a breast carcinoma with metastases to the lungs. She is extremely short of breath. Most of the day she sits in her bed, leaning on her elbow, gasping for breath. She also suffers from nausea. Morphine in relatively high dose does not seem to be successful anymore. Corticosteroids are being added. In the past she had asked for euthanasia several times but her daughters had always been able to persuade her not to have it carried out.

One morning, she has a perforation of the stomach. An IV infusion with omeprazole is administered. That afternoon she keeps on vomiting, while suffering from severe dyspnea. The patient is hardly able to speak. The family argues for euthanasia. The patient is in severe distress. The hospice-physician discusses an increase of sedating drugs. A calm and realistic discussion makes the family members change their minds on euthanasia and accept sedation as an option. After having said farewell to their mother and wife, the morphine and midazolam doses are increased. The patient becomes calm and is not distressed anymore. Also the family calms down and appreciates the care and the atmosphere around them. The patient dies quietly the next day.

As the patient's lungs had been grossly damaged by the growth of the tumor, it was impossible to relieve her dyspnea, without decreasing her conscience. When her family asked the hospice-physician to help their beloved, the physician saw no other alternative to relieve the patient's suffering than to further increase the medication doses. The administration of high morphine and midazolam doses alleviated distress but also rendered this patient unconscious. It is in this sense that the principle of double effect may apply to this case even though it remains questionable (1) whether rendering a patient unconscious in such circumstances should be seen as a moral evil and (2) whether the unconsciousness of the patient (the supposed bad effect) is the means to achieve the good effect. Terminal sedation should first and foremost be seen as a means of relief of refractory (total) pain. Taking the patient's consciousness away is not the physician's intention.

Terminal sedation used to be associated with the hastening of the patient's death (see chapter 8). Recent research has provided good evidence that in this case

it is very unlikely that the patient's life was shortened (Verhagen et al, 1999; Ventafridda et al, 1990). This does not mean however that it was an easy task for the caregivers to render this suffering woman unconscious. In most cases, also here, terminal sedation involves mixed emotions on the side of the patient's loved ones as well as on the side of the caring team. The time to say goodbye is brought about by the administration of the sedatives and separated from the moment of death. Still, the moral ambivalence and uncertainty of this kind of decisions is rather limited.

However, in a small number of extreme cases in hospice practice, terminal sedation will almost certainly shorten the patient's life. And in such cases, it may be hard to discern intentions and unwanted side-effects. The next case is illustrative in this respect.

Case 2: The limits of palliative care

A 50-year-old homeless man with a history of drug abuse and psychopathology had developed a malignant tumour from neurofibromatosis. He was diagnosed with a growing sarcoma in the left buttock. He was referred to the hospice at an early stage of the disease. The tumor was growing slowly, invading the sacral nerves but not metastasising. During a relatively long period morphine, carbamezapine, phentanyl, ketamine and buppivaccaine were administered both subcutaneously and intrathecally and appeared successful for a while. However, his pain returned time after time. This made it almost impossible for the team to establish a consistent strategy of pain and symptom management. When in pain, the patient was screaming loudly, demanding euthanasia. However, the days the pain was absent he explicitly rejected euthanasia. As this situation lasted for several months the team, together with the patient, began to burn out. During the last days of his life he suffered excruciating pain and sedation was considered. As levomepromazine 250 mg/24hours sc was unsuccessful, barbiturates were administered but the dose was insufficient to sedate him. He kept suffering from severe pain. The dose of barbiturates was increased, which made the last hours of the patient's life bearable. Semi-conscious, he said goodbye to the team and died peacefully.

In this case, and contrary to the first case, it is very likely that the high dose of barbiturates hastened the death of this patient drastically. From a theoretical perspective, the principle of double effect applies here too. The direct effect of the administration of the sedative medication is the relief of the patient's suffering.

The indirect effect is the hastening of the death of the patient. Furthermore, the good effect, the relief of suffering, was immediately caused by the sedation and not resulting from the bad effect, the hastening of death. Finally, the administration of barbiturates can in itself, independent of its effects, not be considered as morally evil (Boyle, 1980). The morality of sedation illuminates the moral meaning of the principle of double effect (Cherny and Portenoy, 1994). Proponents of euthanasia often argue that in everyday practice, intentions are not so clearly distinguishable as the principle of double effect seems to imply. However, in hospice practice, where euthanasia is considered as a 'Rubicon', the distinction between euthanasia and unintentionally hastening a patient's death is crucial.

The theoretical tenability of the principle of double effect, does not mean that this particular case was unproblematic. It put a heavy strain on the caring team. All care-givers felt burnt out. Because of the emotional instability and manipulative attitude of the patient, it was extremely hard to develop a compassionate attitude towards him. In a review carried out afterwards a discrepancy was observed between the caring attitude of the team and the psychopathology of the patient. The latter required a specific tough approach with which the team members had not much experience. Therefore, a clear strategy of care, in order to deal adequately with the patient's needs and wishes, remained absent.

Another problem concerned the intractability of the patient's pain. This intractability did not only come from his clinical picture and his history of drug abuse. Also his attitude towards his pain, and by that the character of his pain itself, differed radically from one moment to another. Sometimes he appeared to be able to tolerate the pain. Other times, especially during the nights, he was screaming for a doctor to come and relieve his suffering, thereby awakening other patients.

The team's inability to deal with this patient's needs together with the intractability of his pain led to the eventual decision to sedate the patient. Even though the principle of double effect can justify the decisions taken, it cannot be denied that there is an appearance of pragmatism in the attempts to sedate this patient. The suspicion arose that the caring team would be quite pleased if the sedation hastened the patient's death. As euthanasia is often criticised as a poor solution when there is a shortage of palliative care (Roy and Rapin, 1994), in the experience of the caring team this case could be criticised for the same reason. One of the main aims of hospice-based palliative care in the Netherlands is to reduce the high number of euthanasia cases, through compassionate care. In this case this aim was frustrated. This frustration can hardly be explained by moral theory. Only by taking into account the practice of palliative care with its range of emotions, attitudes and habits, can the problems of this case be understood.

Case 3: Withdrawing life-sustaining treatment

In chapter 6, the case of the 58-year-old divorced female lawyer, who suffered from a bronchus-carcinoma with brain metastasis, was extensively described. Here follows a summary. During the first conversation she had with the hospice physician, months before she was admitted to the hospice, she stated that she wanted euthanasia if her suffering became unbearable. The hospice physician informed her gently that although this option was not available in the hospice he would never abandon her. If she would persist in her request, she could be transferred to the hospital.

At the time of admission to the hospice she was suffering from pain which decreased after a short time. After an emotionally difficult period, she started to enjoy life in the hospice, saying that for the first time in her life she finally was able to get rest. Everyone who spoke to her regularly noticed how well she developed emotionally and how she became more and more able to give voice to her many 'soul wounds' of the past. Her relationship with her two daughters grew more intense than ever.

However, the time came when her energy started slipping away. She wanted to die. Because of increasing headache and nausea a corticosteroid called dexamethasone was proposed. She refused it as she was afraid of its life-prolonging effects. Only later, when the symptoms became aggravated, did she agree to have corticosteroids. This relieved her suffering. However, she became more and more tired. Again, she explicitly requested euthanasia. She wanted to be transferred to the hospital. In an emotional discussion with her daughters the hospice physician proposed discontinuation of dexamethasone and the control of her pain and nausea by alternative measures. She was relieved by this proposal as her two daughters both disliked the idea of euthanasia. She died peacefully four days later, under sedation.

25 % of all patients admitted to Hospice Rozenheuvel state they want euthanasia when suffering becomes unbearable (Zylicz and Janssens, 1998). However, between 1994 and 1998, only two hospice patients out of 571 have persisted in their wish; they were eventually transferred to the hospital to undergo euthanasia.

In palliative care the assessment of the patient's reasons to request euthanasia is paramount. In this respect the public nature of the Dutch euthanasia debate enhances the openness of the communication between the physician and the patient with regard to euthanasia. Placing the needs and wishes of the patient in the centre requires an absence of taboos. In palliative care, the patient should feel free to discuss all relevant concerns with the carers.

This patient uttered two euthanasia requests to the hospice physician. The first one was made well before her admission. It appeared to stem from an urge to remain in control and to be independent. This attitude had characterised her entire life. Her urge for control and independence clearly remained present during the first week of her stay in the hospice. Only when she came to feel at home in the hospice did she learn to accept her dependence on the caring people surrounding her. She became able to deal with her soul wounds of the past. In these two months she never repeated her request for euthanasia. When she felt that everything was said and done, she started to deteriorate and began to feel burnt out. A second euthanasia request came up but this time for different reasons.

As one of the effects of the corticosteroids was life prolongation it seems questionable to regard the administration of corticosteroids as futile from a medical point of view. However, futility of medical treatment does not only relate to the medical realm but is situated in the larger context of the needs and wishes of the unique individual. Medication with the primary function to postpone death can be considered futile in palliative care if the patient no longer experiences any benefit. The assessment of futility requires extensive discussion with the patient and her/his family to find out whether the treatment is beneficial. As this patient was burnt out and ready to die it was decided, after ample discussion, to discontinue dexamethasone. In her immediate reaction to this decision the patient said to the hospice physician: "So I don't have to undergo euthanasia?" It thus appeared that she never really wanted to be killed.

Case 4: Euthanasia

A 55-year-old man was suffering from a bladder carcinoma. He had excruciating colic pain and constipation. Together with his general practitioner he was seen at home by the hospice physician. The hospice physician advised phentanyl 10 mg/24 hours, which is already a high dose. At the same time efforts were made to activate colon movements and treat constipation. When the patient's pain did not diminish the general practitioner, without further consultation, increased the dose of phentanyl, which however also increased the colic pain. He did not pay attention to the constipation. After several pain attacks the patient requested euthanasia because of his excruciating pain. When the hospice physician was informed about the decision of the patient he rushed to the patient's home. He prescribed other medication which decreased the cramps. When euthanasia was performed by the general practitioner, the patient was almost free from pain.

His wife and his daughters were opposed to their loved one's decision. His son, however, supported his father's decision. After the husband's death, his wife got severely depressed. She was cared for by the hospice bereavement team.

This case illustrates the findings of a recent report that evaluated the notification procedure with regard to euthanasia (Van der Wal et al, 1996; Van der Maas et al, 1996; Hendin et al, 1997). According to this study in 88 % of all 3200 annual euthanasia cases the treatment at that time was palliative in character. In 83 % of all cases the euthanising physician stated that treatment alternatives were no longer available. According to the physicians these patients were suffering unbearably and irreversibly. The inability to palliate the suffering of these patients was the main reason behind the decision in favour of euthanasia or physician-assisted suicide.

As mentioned above, there is a broadly shared acknowledgement that much can be improved with regard to palliative care in the Netherlands and this case highlights the necessity of this improvement (Zylicz, 1996). Increasing the doses of phentanyl by the general practitioner to diminish the colic pain of this patient led to a reverse effect. Presumably, if the general practitioner had had better knowledge of pain and symptom control (or if he had consulted the hospice physician more often) this case of euthanasia could and would have been prevented.

Furthermore, the role of third parties in this case, notably the son of the patient, may well have infringed the autonomy of the patient's request. It remains questionable whether, on the day of the patient's death, just when his pain became bearable for the first time in weeks, his euthanasia request was really autonomous. The idea that palliative care takes the patient and his/her loved ones as the unity of care, may turn out to be an ideal. Not all family members wish to be cared for, and not all family relations are close and loving (Janssens and Willems, 2000).

Finally, one other consideration deserves attention. Euthanasia may have profound and still unpredictable effects on the bereaved. Following a loved one's death by euthanasia, psychopathological symptoms may well occur in the bereaved (Zylicz and Janssens, 1998). The maltreatment of this patient's pain, which eventually was the reason for having euthanasia carried out, was for the patient's wife a terrible experience. It illustrates the importance of bereavement services by the people who cared for the deceased (Murray Parkes, 1996).

Conclusion

Palliative care practice is pervaded by complex moral problems. In this chapter some of these problems, directly and indirectly relating to euthanasia, have been

discussed. It is important to note that the concept of palliative care was developed out of moral motivations. The foundation of St Christopher's Hospice in 1967 by Dame Cicely Saunders arose from two moral discomforts (see chapter 2). First, there was a moral discomfort with mainstream medicine. Many people became aware that care for the terminally ill was seriously underestimated in mainstream health care. Medicine focused primarily on technological interventions and repair of bodily disorders. Its main goal was cure. If cure was not possible, prolongation of life became imperative. Second, there was a moral discomfort with the growing influence of the British Voluntary Euthanasia Society which pleaded for the legalisation of euthanasia. Terminal care holds the middle between these forces: in principle, nothing is done to postpone or hasten death. Life-prolonging treatment, which is potentially harmful for the well-being of terminal patients and which can make the acceptance of their situation more difficult, is deemed futile. Intentionally hastening death is regarded as dangerous and unnecessary since patients' requests for euthanasia are often ambivalent and preventable in the context of good palliative care.

Note

* Modifications in comparison to the published article:

- Paragraph 1 of this chapter focuses on the organisation of hospice care in the Netherlands whereas in the published article focus was on the status of palliative care in the Netherlands in general (which is the subject of chapter 4).
- Case 1 was added, stressing new insights that terminal sedation in most cases does not shorten the patient's life.
- Case 3 has been summarised in order to avoid overlap with chapter 6.

CHAPTER 8

TERMINAL SEDATION IN PALLIATIVE CARE PRACTICE

AN ETHICAL EVALUATION

This chapter has been submitted for publication as:
Janssens MJPA, Gordijn B, ten Have HAMJ, Terminal sedation in palliative care practice. An ethical evaluation.

TERMINAL SEDATION IN PALLIATIVE CARE PRACTICE

AN ETHICAL POINT OF VIEW

Introduction

For a long time, the ethical debates on medical decision-making at the end of life have focussed on the morality or immorality of euthanasia. Since the rise of modern medical ethics in the late 1960s, arguments pro and con have addressed the patient's autonomy on the one hand and the physician's duty to do well on the other. Since only recently, more attention has been paid to the question of the preventability of euthanasia, especially in the light of further developments in palliative care. Evidence suggests that most requests for euthanasia disappear when good palliative care is provided (Gordijn and Janssens, 2000). A central question refers to what should be done if the suffering of a patient persists in spite of good palliative care. Are euthanasia and physician-assisted suicide at the request of the patient morally justified in such cases? Should alternatives be sought even if the patient has autonomously and repeatedly requested for euthanasia or physician-assisted suicide? And if so, what kind of alternatives? And what if these alternatives, such as high doses of medication, or withdrawal of artificial hydration and nutrition, are likely to lead to a sooner death? Many aspects of this ethical debate have remained unclear. Unclear has remained what terminal sedation amounts to in the first place. Especially the adjective 'terminal' seems to suggest that termination of the patient's life may be the aim of the physician administering the sedatives. An unresolved issue relates to the role of intentions for the morality of our acts and the ethical validity of the so-called doctrine of double effect. Unresolved remains also what should be done if the patient persists in his/her request for euthanasia when the option of terminal sedation is offered. And finally, still unresolved is the issue of withholding artificial hydration and nutrition from the terminally sedated patient. Much unclarity still circles around the plausibility of moral differences between terminal sedation and euthanasia.

In this chapter, the ethical debate on medical decision-making at the end of life, particularly with regard to presumed moral differences between terminal sedation on the one hand and euthanasia on the other hand will be analysed and evaluated (possible moral differences between euthanasia and physician-assisted suicide fall outside the scope of this chapter). Both acts are often called 'means of last resort', indicating that they are only justifiable if a patient's pain, whether it be of a physical, emotional, social or spiritual nature, persists in spite of the best

palliative modalities. There is broad agreement that terminal sedation as well as euthanasia should be prevented through good palliative care where- and whenever possible. Debates start when a patient's suffering becomes refractory.

Basically, three general positions with regard to the morality of the application of these means of last resort can be found in the literature. In the first paragraph, a summary of these positions will be given. One position holds that in palliative care, terminal sedation is the only means of last resort and that euthanasia cannot be part of palliative care. A second position holds that in some cases, euthanasia can be part of palliative care, even though terminal sedation is to be morally preferred. A third position holds that, from a moral point of view, terminal sedation is indifferent from euthanasia and that both practices can be part of palliative care.

After having summarised these positions, It will be argued in the second paragraph that the third position is untenable, referring to two moral beliefs that are firmly rooted in the morality of any civil society. The first moral belief tells us that intention is a relevant criterion for determining the morality of an act. The second belief says that the termination of another person's life is either a prima facie or an absolute evil. If one agrees with these beliefs, one cannot hold that euthanasia and terminal sedation are morally indifferent. In the third paragraph, it is discussed whether terminal sedation can be a better alternative to euthanasia as the first and second positions imply. Based on the moral beliefs analysed in the preceding paragraph, it will be argued that the use of terminal sedation as a means of last resort in palliative care is a morally better alternative for euthanasia. The issue of terminal sedation deserves therefore more attention in the debates on medical decision-making at the end of life than it has received so far.

1. Ethical comparison of terminal sedation and euthanasia

In this paragraph, the three most widely held positions regarding moral comparisons of euthanasia and terminal sedation will be analysed. One position accepts terminal sedation as a means of last resort and excludes euthanasia from palliative care. Referring to the principle of double effect, it is argued within this position that, even if terminal sedation would shorten the life of the patient, this is by no means the intended outcome but merely a foreseeable side effect of the treatment of refractory pain or suffering. The second position holds that, under particular circumstances, euthanasia can be justified as component of palliative care. According to this position, the doctrine of double effect has validity in justifying terminal sedation (which is therefore to be considered morally preferable

over euthanasia) but in some cases of overriding force, active euthanasia should be seen as the only humane alternative. The third position holds that terminal sedation is morally indifferent from euthanasia and that principally both can be part of palliative care. According to this position, the doctrine of double effect is untenable for instance because there is no moral difference between intending and foreseeing an outcome. The theory that both terminal sedation and euthanasia should be excluded from palliative care will not be addressed since recent literature holding this theory is non-existent.

1.1. Terminal sedation as the only means of last resort

Sometimes, even the best of palliative care cannot relieve a patient's distress to a tolerable degree. It is argued that this almost exclusively happens when the patient is imminently dying (Dunlop et al. 1995). In such cases, when all other palliative modalities have failed or are no longer successful, terminal sedation can be offered as an option. Terminal sedation can be defined as "deliberately inducing and maintaining deep sleep, but not deliberately causing death in specific intractable circumstances" (Chater, 1998, p. 257). The patient is put to sleep through administration of morphine (which is not a proper sedative but can, when given in high doses, sedate patients as a side effect), benzodiazepines or barbiturates (which are proper sedatives) (Cherney et al. 1994).

In the literature there is some ambiguity with regard to the life shortening effects of sedative medication. Ventafridda et al. have argued that terminal sedation does not shorten life (Ventafridda et al. 1990). Verhagen et al. even indicated that terminally sedated patients may have a longer life expectancy than a comparable group of non-sedated patients as the relief of suffering may have a positive impact on the often exhausted bodies of the terminally ill (Verhagen et al. 1999). However, Truog et al. have argued that there is at least a risk that life is shortened by terminal sedation (Truog et al. 1992). And Orentlicher writes: "In most cases terminal sedation shortens the patient's life by only hours to days, but it may shorten life by as much as several weeks" (Orentlicher, 1997, p. 1237). Wilson et al. found in interviews with physicians that "many … considered hastening death a possible, if not likely, consequence of administering sedatives and analgesics due to their hemodynamic and respiratory depressant qualities" (Wilson et al., 1992, p. 953). The literature is not clear as to the life shortening effects of terminal sedation. However, taking into account the sometimes extremely high doses of pain medication used to render the patient asleep (Zylicz and Janssens, 1998), and taking also into account the respiratory depression that is

often caused by high doses of morphine (Sulmasy and Pellegrino, 1999; Inturissi, 1990), it seems reasonable to conclude that terminal sedation at least carries a risk of life shortening effects. This conclusion supports the ethical literature on terminal sedation which has addressed the principle of double effect in justifying the administration of high doses of sedatives.

Another ambiguity in the literature relates to the subject of dehydration in the terminally sedated patient. In most countries, artificial nutrition and hydration in the terminally sedated patient are withheld because they do not serve the patient's comfort any longer. The vast majority of terminal patients who are dehydrated do not experience negative effects as long as adequate mouth care is provided (Ellershaw et al. 1995). In some cases hydration would even be contra-indicated as the negative effects of hydration, such as edema and dyspnea, outweigh the benefits. According to some, only in very few cases hydration should be continued in the terminally sedated patient, for example because the family requests so (Dunlop et al. 1995). Others are used to continue hydration in the terminally sedated patient (Morita et al. 1996).

Opinions on dehydration in the terminally sedated patient vary to a great extent. Craig for example has stated that policies of dehydration in the terminal phase are dangerous from an ethical, legal and medical point of view (Craig, 1994). She expressed her concern that it is hard to determine whether or not a patient is imminently dying. She also suggested that deep sedation and dehydration are sometimes initiated where other means of relief of suffering may have been effective. One example would be a patient with a reversible confusional state who is mistakenly assumed to suffer from terminal delirium. Moreover, she argued that dehydration in the terminally sedated patient cannot be justified with the doctrine of double effect. If one of the side effects of terminal sedation is that the patient is unable to take fluids, this can easily be treated by starting artificial hydration. The possibility of the patient dying from a lack of fluids can be prevented without causing harm. It is not argued that dehydration would never be an option but, according to Craig, a policy of dehydrating terminally sedated patients is at least in danger of becoming a cloak for euthanasia. Also others support the view that, when a patient is no longer capable of taking fluids *because* the doses of medication have induced sleep, dehydration in a terminally sedated patient is from a moral point of view the same as euthanasia (Orentlicher, 1997).

One other issue in the debate concerns the question whether terminal sedation to relieve physical pain is morally different from terminal sedation to relieve emotional distress in terminal illness. It can be concluded from the literature that sedation to treat emotional and spiritual distress is relatively common practice. Research conducted by Chater et al. revealed that 10 % of palliative care

physicians had sedated patients for emotional and spiritual distress (more than one reason could be given) (Chater et al. 1998). 14 % of the respondents had sedated patients to relieve anguish. Stone et al. found that sedation was indicated for relief of mental anguish in 8 out of 30 patients (again, more than one indication could be given) (Stone et al. 1997).

Responding to a case discussion presented by Billings and Block, Mount gave three reasons why physicians should be more hesitant to provide sedation as a means for mental suffering than they are for physical suffering (Billings and Block, 1996; Mount, 1996). First, physicians' understanding of psychological and spiritual suffering is more primitive than in cases of physical suffering. Second, physicians are generally more uncomfortable in dealing with psychological and spiritual distress. Third, the presence of psychological and spiritual suffering does not indicate the presence of far advanced physiological deterioration. According to Mount, sedation for persistent psychological or spiritual suffering can be morally justified if no other modalities are available. Others have expressed similar concerns (Cherny, 1998; Rosen, 1998).

The position elaborated on above is based on an adherence to the principle of double effect. Intentional hastening of death is considered to fall outside the scope of medicine. Pain relief, even to the point that life shortening effects can be foreseen, is considered ethically sound as long as the life shortening effects are unintended. Artificial hydration and nutrition are considered medical treatments which can be withheld if they no longer serve the patient's comfort and if the patient's family agrees. Straightforward policies, rejecting the use of artificial hydration in a terminally sedated patient, are considered dangerous by some authors. The same goes for terminal sedation as a modality to treat refractory emotional or spiritual distress.

1.2. Euthanasia as a means of last resort when the option of terminal sedation fails

Currently, euthanasia is illegal in all countries of the world. Also in the Netherlands, up to now, euthanasia is prohibited by law, even though it is tolerated under specific circumstances (Ten Have and Welie, 1996). In the USA, two Appeals Courts have held that two state laws banning assisted suicide are unconstitutional. This decision was rejected by the US Supreme Court in 1997 which held that euthanasia and physician-assisted suicide should be distinguished from the withdrawal of life sustaining treatment and terminal sedation (Burt, 1997). In 1995, in the Northern Territory, Australia, euthanasia was legalised for

some time but this legalisation was fairly rapidly overruled by the Federal Government (O'Connor, 1998). Even though the Netherlands are currently the only country in the world where there is an official policy of tolerance, it is safe to say that euthanasia and physician-assisted suicide also occur in other countries (Emanuel et al. 1998; Quill, 1991; van den Akker et al. 1997).

It is remarkable that most people working in the area of palliative care are firmly opposed to euthanasia. When Cicely Saunders established St Christopher's hospice in 1967 it was partly out of a moral discomfort with tendencies in British society in favour of legalisation of euthanasia. The hospice movement which, following the establishment of St Christopher's, has spread world-wide has always wanted to show that through good palliative care requests for euthanasia can be prevented and that requests for euthanasia can be dealt with humanely without actually having to meet these requests (Twycross, 1995).

Most, if not all, proponents of euthanasia share a good deal of these views. The term 'proponent' may even be inadequate. A 'proponent' writes: "No one is *for* euthanasia ... They perform or sanction them [i.e. cases of euthanasia RJ] as lesser evils ..." (Boisvert, 1988, p. 117) Also 'proponents' would admit that euthanasia can and should be prevented through good palliative care (Quill, 1991; Angell, 1997). They would admit that a well-considered and persistent request alone is not sufficient to justify euthanasia and that, if this request can be taken away through good care, it is imperative to do so. In the Netherlands, only one third of the 9600 annual requests for euthanasia are granted (Van der Maas et al. 1996). Arguably, the opinions of the physicians on the degree of suffering of the patient are in most cases decisive, instead of the request of the patient (Ten Have and Welie, 1996.)

The debate between 'opponents' and 'proponents' thus starts only in cases in which the best of palliative care has failed to control suffering. Physicians who accept euthanasia as a possible means of last resort in palliative care may inform the patient of the option of terminal sedation in the belief that this is to be preferred over euthanasia. But, even if a physician would prefer the option of terminal sedation, this option may not be humane for some patients. Situations of overriding force can be conceived of. In such situations, acts which seem wrong at first sight become permissible. Quill mentions for example patients with uncontrolled bleeding, obstruction from nasopharyngeal cancer, and refractory AIDS diarrhoea (Quill, 1997). For the family, it would be an intolerable burden to watch their sleeping loved one die in such a degrading way. In practice therefore, it may happen that patients suffering from refractory pain and symptoms will persist in their request for euthanasia or physician-assisted suicide, even if the option of terminal sedation is offered as a better alternative in the opinion of the

physician. Patients may not want to be put to sleep, knowing that they won't wake up anymore. For patients and their loved ones, the moment of farewell is separated from the moment of death, sometimes for a period of days or (if hydration is started) even weeks.

The decisive argument to consider euthanasia or physician-assisted suicide a means of last resort in palliative care, refers to the unbearable and hopeless suffering of some patients in spite of adequate palliative care. The presence of a well-considered and persistent request only, is not considered decisive for action. But if a patient, suffering unbearably and hopelessly, wants to die but refuses to be sedated, it can be argued that physician-assisted death is the only humane alternative, even if the physician holds terminal sedation as a morally better alternative.

1.3. Euthanasia and terminal sedation are morally indifferent and both acceptable in palliative care

Against the first and second positions, it is argued that, from a moral point of view, terminal sedation is indifferent from euthanasia. Three argumentation strategies are used.

From a consequentialistic point of view, it is argued that intentions are by no means decisive for the morality of actions. What is decisive, according to consequentialists, is the balance between benefits and harms. The act is morally praiseworthy if it leads to more benefit or less harm than was the case before the act was performed. In an analysis of a case of an old, severely ill woman with whom antibiotics to treat a pneumonia were withheld, Singer argues that it would be untenable to hold that the doctor who gives the injection is a murderer while the doctor who decides not to administer antibiotics is practising good and compassionate care (Singer, 1993). In this consequentialistic way of thinking, the doctrine of double effect cannot be accounted for. Irrespective of the intentions of the actor, irrespective of whether the effects were intended or not intended and merely foreseen, the morality of an act is judged according to its consequences. According to Singer we have to take equal responsibility for intended as well as unintended, foreseen effects. The consequence of terminal sedation is that the patient will die in some days, at least if the patient is dehydrated. The consequence of euthanasia is that the patient dies within the hour. In both cases, the pain and suffering of the patient are relieved. Provokingly, it is also argued that the principle of double effect itself implies a disguised adherence to a consequentialistic way of thinking. Negative but foreseen side effects of an act

cannot be unintentional. They should be conceived of as costs proportionate to a benefit obtained. But costs can never be unintentional. Before deciding to act, a cost-benefit calculation is made which makes it impossible to state that costs are unintended (Donagan, 1991). Hastening of death is namely only accepted when the quality of a patient's life is below a certain level. This is in other words, according to Singer, not a decision based on acceptance of the sanctity of human life, but a decision based on a disguised quality of life judgement (Singer, 1993). If that is so, terminal sedation and euthanasia are not morally different.

Similarly, a second argumentation strategy follows the *via negativa*. In a coherent line of reasoning, it is said, the main arguments used against euthanasia should also be directed against terminal sedation. Let us consider three arguments often used against euthanasia. First, the argument that opening the door for physician-assisted suicide or euthanasia is likely to lead to abuse (i.e. the slippery slope argument) would also have to be directed against terminal sedation. Terminal sedation is mostly considered a means of last resort, only justified when good palliative care has failed to relieve pain or suffering. It can be questioned however whether the criterion of refractory pain and suffering is not vague enough to be widened time after time. Euthanasia is often criticised as 'an easy way out'. Permitting euthanasia may hinder the creative process of finding better palliative modalities to relieve suffering (Foley, 1997). But it can be argued that by permitting terminal sedation as a means of last resort, the door providing an easy way out is already open. In other words, where permission of euthanasia is often rejected with the slippery slope argument, the same argument may be used against terminal sedation. Terminal sedation and euthanasia are both in danger of becoming simple solutions for complex problems that may have been preventable by better palliative care. Second, the moral relevance of the so-called passive-active distinction, which holds that allowing to die would be morally permissible whereas actively shortening the life of a patient would be morally impermissible, can be criticised. Terminal sedation is clearly an act and not an omission. However, more difficult to defend is the practice of dehydrating a terminally sedated patient. It can be argued that there is nothing passive about deciding to withhold hydration in a terminally sedated patient who, as a result of the sedation, is no longer able to take fluids. Using the passive-active distinction as an argument to oppose euthanasia and condone dehydration in these circumstances can be said to be incoherent (Brody, 1995). Third, permission of euthanasia is said to be dangerous as requests for euthanasia are in most cases multi-layered. Instead of being voluntary, they may be caused by fear of an inhumane dying process, depression, pain, or guilt (Zylicz and Janssens, 1998; Chochinov et al. 1995). And since the patient's choice to die is not made freely, it would be wrong for

physicians to act upon this choice (Campbell, 1999). However, empirical evidence suggests that the reasons for terminal sedation are similar (Chater, 1998). If euthanasia is rejected by pointing towards the ambivalence of many patients' requests, terminal sedation can be rejected for the same reasons.

The third argumentation strategy used to indicate that terminal sedation is indifferent from euthanasia focuses on the patient's autonomy. It is argued that the morality of terminal sedation is based first and foremost on the informed consent of the patient, and not so much on the intention of the physician (Quill, 1997). The autonomous wish of a patient to have life sustaining treatment withdrawn has to be met by the physician, irrespective of the latter's intentions. So why, it is argued, do these intentions become so crucial if they are related to an act instead of an omission? Is not autonomy a more important condition for the justification of terminal sedation than the intentions of the physician? In countries where euthanasia is not tolerated, terminal sedation and/or dehydration may be the only way to meet the autonomous request of a patient to put an end to his/her suffering (Sahm, 2000). In these cases, the autonomous wish of the patient to put an end to his/her suffering would be decisive, not the intention of the physician. If this is crucial, the means through which the patient's suffering is ended are of secondary importance. Terminal sedation and euthanasia are therefore said to be principally both justified if there is an autonomous request of the terminal patient.

2. Terminal sedation and euthanasia are morally different

It will be argued here that euthanasia and terminal sedation are morally different on the basis of the moral value of human life and on the basis of the moral relevance of intentions for the morality of our acts.

The view that it is prima facie wrong to take another person's life is solidly rooted in the morality of any civil society. Moral experience, formed and shaped by the traditions in which we live, simply tells us that human life has value in itself. The act of killing another person is therefore simply a prima facie evil, irrespective of its consequences. It does not suffice to base it exclusively on external arguments (for instance the slippery slope argument). It is always based on deontological arguments too. Advocates of euthanasia will consider the prohibition to kill as a prima facie norm (Campbell et al. 1995), whereas some opponents of euthanasia will consider it absolute (Boyle, 1991). Both groups will acknowledge that there are situations in which one is compelled to choose between two evils e.g. letting the patient suffer intolerable pain or shorten the life of the patient. In justifying the latter evil, the principle of double effect is crucial for opponents of

euthanasia but, as will be argued below, its use does not necessarily have to be limited to this group only. According to the principle of double effect, harming someone is only justified if it is not intended and if their are compelling reasons to bring it about. The act itself must be morally right or at least neutral and the evil brought about may not be a means for the good effect.

Applying the doctrine of double effect in the context of terminal sedation implies that the shortening, or terminating of a person's life is considered a moral evil, independent of the concrete circumstances and independent of the consequences. It has to consider the shortening of a patient's life either a moral evil in itself, or a moral evil based on culturally shared norms and ideals that define the limit of self-sovereignty (Jennings, 1991). The (im)morality of euthanasia does not (only) depend on whether the patient has given his autonomous consent or on what the societal consequences will be of a tolerant euthanasia policy. If one adopts the doctrine in the debate on terminal sedation, then it follows that one considers euthanasia a moral evil independent of the concrete circumstances. Boyle even goes a step further arguing that the tenability of the doctrine of double effect relies on an absolutist theory (Boyle, 1991). In Boyle's view, the doctrine has to accept absolute, exceptionless norms, prohibiting certain harms. The doctrine only acknowledges that situations can arise in which the infliction of a prohibited harm is unavoidable and in such situations the distinction between intentional harming and unintentional harming serves to limit the extension of the prohibition. In this context, it would imply according to Boyle, that protagonists of euthanasia, who hold the norm not to kill as a prima facie norm, cannot use the principle of double effect in justifying terminal sedation. It can be doubted if this is so. It is for most of us not hard to conceive of situations in which the taking of another person's life would be the lesser of two evils. This alone would provide sufficient reason to hold the norm not to kill as a prima facie norm instead of an absolute norm. Moreover, at least a substantial part of the people who hold euthanasia as a means of last resort in palliative care argue that euthanasia should be avoided where- and whenever possible through good palliative care (Miller, 1995; Quill et al. 2000). According to them, the termination of a patient's life is prohibited unless all other alternatives have failed. It is too simple to say that for them terminal sedation is not such an alternative under circumstances to be preferred to euthanasia. Proponents as well as opponents of euthanasia may justify terminal sedation with an appeal to the principle of double effect. Also proponents of euthanasia may hold that (1) the taking of another person's life is prima facie evil and that (2) the intention of one's act can play a decisive role in evaluating the action from a moral point of view. And thus, it is possible to argue that for them, terminal sedation is a preferable alternative to

euthanasia, even though in the end euthanasia may under circumstances of overriding force be considered the only humane alternative.

Against the consequentialistic point of view that terminal sedation should be understood as a trade off between the benefits (relief of pain and suffering) and the foreseen harms (the shortening of life) and that, thus, the harms cannot be unintended, the following can be argued. Foreseeing an effect of one's act is not the same as intending it. If, in retrospect, it would appear that the good effects of one's action had not occurred and the bad effects had, one would regret one's act because one's intention had not come out. Intentions relate to what one wants to result from one's act. One does not want to bring about foreseeable harms but one accepts them because a proportionately grave reason is present. It cannot be argued that negative effects which one could avoid if it were possible, are part of one's intentions.

Consequentialists may also argue that intentions are irrelevant for the morality of one's acts in the first place but this argument runs clearly against common sense morality. Morality is not a mathematic calculus only concerned with maximising goods and minimising harms. Morality is based on moral experience. And moral experience tells us that it matters whether a good effect of an act is intended or just co-incidentally brought about.

One, more practical, objection to the role of intentions in moral evaluation is that the intention of a physician can never be assessed by someone other than the physician (Cavanaugh, 1996; Thorns, 1998). Physicians who terminally sedate a patient can have the intention of shortening the patient's life without anyone ever being able to find out. This is true, but only to some extent. In retrospect, the act itself can give clues. Was the dose of the sedatives proportionate to the desired effect? How fast did the physician increase the dose? Did (s)he assess whether pain and symptoms were adequately under control before increasing the dose of sedatives? Or did (s)he increase the dose every hour without assessing the patient's condition? If the doses were disproportionate or raised without adequate assessment, the condition of proportionality cannot have been met and it would be safe to argue that at least one of the intentions of the physician was the hastening of the patient's death.

If the taking of another person's life is considered a prima facie evil, and if one can make a moral distinction between intended effects and not intended but foreseen side effects, there is a sound basis to evaluate terminal sedation and euthanasia differently. But still, one last difficult issue should be raised in this context. One could argue that even if terminal sedation can be justified with the doctrine of double effect, it is impossible to justify dehydration in the terminally sedated patient. This assumption can be criticised. First, if hydration would be

contra-indicated from a medical point of view because it would cause the patient more harm than good (for instance oedema or dyspnea), hydration would clearly be malconduct. But let us assume that these adverse effects are not expected to occur. In that case, the patient should be informed before the sedatives are administered. In the end, the patient decides. But let us now assume that the patient is incompetent and unable to consent before being sedated. The wish of the patient's loved ones is important but not decisive. The question to be asked is what the reasons are that would justify hydration. Only one reason can be conceived of, namely keeping the patient alive even in a situation in which it does not serve the patient's quality of life. In such cases, the decision to withhold hydration is made because the lengthening of the patient's life is deemed futile, even if the patient's incapacity for oral intake is a direct result from the administered sedatives. It is true that the passive-active distinction is ambiguous. Intentionally shortening a person's life can be achieved through an omission. But an act can never be seen as not lengthening a patient's life (as opposed to shortening a patient's life). An omission can. Dehydration is exactly that and therefore it can not be equated with intentional hastening death. A possible reason to hydrate a terminally sedated patient would be the family's need for time to deal with the oncoming death of their loved one (Dunlop et al. 1995).

3. Terminal sedation as an alternative for euthanasia

In line with the preceding paragraphs, it will be argued here that terminal sedation as a means of last resort in palliative care is a morally better alternative for euthanasia. If intentions matter morally, if terminal sedation is meant to relieve pain and suffering and not to shorten the life of the patient, and if the termination of another person's life is at least prima facie evil, the practice of euthanasia would seem morally indefensible without at least having considered terminal sedation as an alternative (Cherny and Portenoy, 1994; Cherny et al. 1994; Byock, 1993). As for the Netherlands, there is no hard evidence for stating that terminal sedation was or was not considered as an option prior to the 4500 cases of life termination (van der Maas et al. 1996). The relative absence of literature on terminal sedation in the Netherlands may give clues for stating that the option of terminal sedation is not an important issue in decision-making. It seems unlikely that in the above cases, terminal sedation was for some reason not possible. It is therefore probably safe to assume that in many cases either terminal sedation was not presented as an option, or that the patients or their families refused and chose for euthanasia or physician-assisted suicide instead. The first practice is problematic. When a patient is

suffering from intolerable refractory pain or suffering, only few alternatives remain. In those cases, even if there is a well-considered and persistent request for euthanasia, it is a duty to inform the patient of other alternatives, even if only one alternative, i.e. terminal sedation, remains. Experience from a Dutch hospice, where euthanasia is not performed but where patients can be transferred to other health care settings to have euthanasia carried out, suggests that in such cases, patients may opt for terminal sedation. Some want to die but the majority does not want to be killed by the team that has cared for them and has grown familiar with them (cf. chapter 7). Requests of patients are often ambiguous and do not serve as a sufficient basis for euthanasia or physician-assisted suicide to be carried out. Often a more authentic request lies behind the request for euthanasia, a request to have pain and suffering relieved in whatever manner possible. It is imperative to listen closely to the patient and assess whether requests for euthanasia or physician assisted suicide are not based on a request for relief of suffering, even if this can only be achieved through terminal sedation.

However, some patients may prefer euthanasia over terminal sedation. They may consider terminal sedation a degrading way of dying. For their families watching their loved one in an unconscious state may be a heavy burden. But, even though situations of overriding force may arise in which terminal sedation is not a humane option, the autonomous wish of the patient alone is not a sufficient basis to carry out euthanasia. The relevance of a physician's intentions together with the common belief that it is prima facie evil to terminate another person's life may make it impossible for him to meet the patient's preference. These two arguments, both entailed in the doctrine of double effect, are central in considering terminal sedation a morally better modality than euthanasia in palliative care. All other arguments either fail or can rightly be used against terminal sedation as well.

Conclusion

Terminal sedation should be considered as a morally defensible modality in palliative care. In daily palliative care practice, it is not often indicated. Only if the patient is suffering from intolerable and refractory pain or suffering it is a justifiable option. Terminal sedation and euthanasia can and should be distinguished from a moral point of view. First, because moral experience tells us that it is, at least prima facie, wrong to kill another person or shorten another person's life. Second, because intentions are relevant for the morality of one's acts.

It is common practice not to hydrate a terminally sedated person. Arguments rejecting this practice eventually fail even though a standard policy dehydrating

terminally sedated patients is not advisable. If the patient is incompetent and unable to give consent to dehydration before the sedatives are administered, it is crucial to uphold the distinction between shortening life and not prolonging life. For terminally sedated patients, there is no duty to prolong their lives. Artificial hydration can be considered a futile medical treatment, to be consented to if possible, to be withheld in most cases where consent is not possible. In exceptional cases, the family may opt for artificial hydration, for instance if they need time to say farewell to their loved one.

If terminal sedation should not be identified with the termination of another person's life and if it is morally defensible that termination of another person's life is, at least prima facie, wrong, terminal sedation is an acceptable alternative to euthanasia. Carrying out euthanasia is morally problematic if terminal sedation is not presented as an option. Offering a patient the alternative of terminal sedation may take away the request for euthanasia, as many patients do not want to be killed. But even if they reject terminal sedation, autonomy alone is not a sufficient reason for carrying out euthanasia.

CHAPTER 9

CLINICAL TRIALS IN PALLIATIVE CARE

AN ETHICAL EVALUATION

A slightly modified version of this chapter was published as*:
Janssens MJPA, Gordijn B, Clinical trials in palliative care. An ethical evaluation. *Patient Education and Counselling* 2000; 41: 55-62.

CLINICAL TRIALS IN PALLIATIVE CARE

AN ETHICAL EVALUATION

Introduction

Palliative care has been defined as "the active total care of patients whose disease is not responsive to curative treatment. Control of pain, of other symptoms, and of psychological, social and spiritual problems, is paramount. The goal of palliative care is achievement of the best quality of life for patients and their families" (WHO, 1990, p. 11). In an earlier chapter, it was indicated that this definition is unclear as to the scope of palliative care. However, for an ethical analysis of the conditions of possibility of clinical trials in palliative care, it is important to delimit the scope of palliative care. In this chapter, palliative care will be referred to as beginning from the time that curative efforts have been deemed futile. And dying patients are understood as all those who receive palliative care, acknowledging that the time until death may still be quite far away for some of them.

The aim of palliative care is to achieve the best possible quality of life for patients and their families. The medical, psychosocial and spiritual needs of the patient are indicative for the care given. At first sight, experimental trials on the dying seem at odds with the fundamental aim of palliative care. Clinical trials are not intended to achieve the best quality of life of the patient. What is more, they are only ethically sound if there is a proportionately grave reason present to allow for the *harms* that they may inflict on the participants. It is imperative that the medical care for future patients is improved. But improving medical care for future patients implies that current participants in trials are exposed to serious potential harms. Caregivers in a palliative care setting are faced with a conflict between nonmaleficence (not to harm current patients) and social justice (the societal duty to improve medical care for future patients). Both options are imperative and morally praiseworthy but at the same time they seem mutually exclusive. In this chapter however, it will be argued that, on further consideration, the dilemma does not necessarily have to occur.

First, it will be argued that both palliative care and codes concerning experimental research on human beings historically have come forth out of a moral discomfort with mainstream medicine of the late sixties. This short historical overview can explain why clinical trials have become so controversial for caregivers in palliative care. Second, the apparent dichotomy between the aim of clinical trials (enhancement of treatment for future patients) and the aim of

palliative care (providing the best possible care for current patients) will be reviewed by assessing the harms that may be inflicted through participation in clinical trials. Third, it will be argued that there is not necessarily a dilemma. For some patients, participation in experimental trials can be a meaningful enterprise.

1. Historical origins

By the end of the 1960s, medicine became more and more driven by the technological imperative. The increasing role of technology within medicine provided physicians with increasing power over their patients. This process, in the context of a more and more emancipating society, led to counter-reactions from different realms in society (Rothman, 1991). The old professional Hippocratic ethic in which the good of the patient was determined by the physician's views, was unable to deal with the new moral questions of modern medicine. In this time, historical publications laid several cases of misuse of medical power in the open (Pappworth, 1967; Beecher, 1966). Secret clinical trials, in which patients were not informed that they were participating in an experimental study, clearly opposed the moral conscience of the public. Thus, for the newly established medical ethics the principle of patient autonomy became foundational. Patients' rights had to be defended against the risen power of the medical professionals. Codes were formulated to protect the patient in experimental clinical research. The new medical ethics developed as a counter-reaction against medical technological developments.

In this same period, and for very similar reasons, the modern hospice movement was founded with the establishment of St Christopher's hospice in London in 1967. This movement came forth out of a moral discomfort with the care for the dying in mainstream medicine. The rise of medical technologies had led to a health care system which focussed on cure. The care for the dying was neglected. The first hospices redirected attention to the needs and wishes of the dying for whom a lot could still be done. In those days, palliative care developed within in-patient hospices, relatively detached from the formal health care system and also relatively detached from the new medical ethics which, paradoxically, settled comfortably within modern medicine (Zwart, 1995). In the years following the foundation of the first hospices, research in pain and symptom control played a considerable role in palliative care, as the studies of Twycross indicate (Twycross, 1977). The aim of palliative care was to integrate an advanced and scientifically sound approach to the development of pain and symptom control with compassionate care (Saunders, 1978).

However, as palliative care developed further, experimental clinical research became her stepchild. The idea took hold that this kind of research was at odds with the fundamental moral intention of palliative care (Calman and Hanks, 1993). Palliative care distanced itself from mainstream medicine because of a perceived lack regarding the care for the dying. Hence, the needs and wishes of the individual patient set the norm for palliative care practice. Experimental research seemed to put that at risk what was at the heart of palliative care.

Only recently, this negative attitude towards experimental research was challenged (Thorpe, 1992; McQuay and Moore, 1994). Not surprisingly, this shift in attitude coincides with a maturation of palliative care as palliative care is increasingly becoming re-integrated with the formal health care system.

2. Clinical trials in palliative care and the duty not to harm

Clinical trials in palliative care carry with them many practical problems. The number of potential research subjects is small; patients may die in the course of the trial and the number of patients opting out may be high (McWhinney et al, 1994); patients may want to die at home instead of being observed in a clinical setting; patients may be too weak; carers may be inexperienced in the field of research; patients' differing histories of pain treatment make it hard to assess the effects of the experimental treatment (Blackledge and Lawton, 1992). Still, it is acknowledged that these practical problems can be dealt with. Multicentre trials, well designed short-term studies and $n = 1$ trials can provide adequate solutions for the practical problems (Calman and Hanks, 1993). Because solutions are available, palliative care cannot simply point to practical difficulties in refraining from experimental studies. Hence, it is first and foremost an ethical, rather than a practical problem. The moral problems of clinical trials in palliative care can be put in terms of (potential) harms to the patient. Referring to the concept of total care, the violation of the principle of nonmaleficence can occur at three different levels: a physical, a psychosocial and a spiritual level.

2.1. Physical harms

Patients participating in clinical trials may be physically put at risk. In phase I studies severe suffering or even death may be caused by high toxicity of the experimental treatment. A beneficial response (for example tumor reduction) to phase I experiments hardly ever occurs. The vast majority of patients suffers more from (the side-effects of) the experimental treatment than benefit from it (Holdener

et al, 1992). After all, in phase I and phase II studies, little or nothing is yet known about the side-effects of the experimental treatment. In randomised phase III studies, patients in the experimental group may well be administered suboptimal treatment (Max and Portenoy, 1993).

In short, the physical risks of patients participating in clinical trials are considerable. If one presumes that the duty not to harm is paramount in palliative care, clinical trials seem incompatible with palliative care.

2.2. Psychosocial harms

Many dying patients in palliative care enjoy their lives. Some even state they experience the best time of their lives. The dying process can, for the dying patient as well as for his or her loved ones, be an extremely valuable time of personal fulfilment. After a long and hard search for meaning, many patients have finally accepted their nearing death and are now able to enjoy the small things of life. For some patients this can be a revelation they have never before experienced (Skinner, 1986). More and more patients are able to die at home, finally having left the medical circuit. Facing the end of their lives they are now able to tell the narrative of their lives. Only when death is not far, it is possible to see life as a narrative, with a beginning, a plot and an end (Ricoeur, 1991).

However, by participating in experimental research, many patients will be forced to remain within the medical circuit. If not required to spend their time within medical institutions, at least they must be observed regularly within the medical institutions. For many patients participation in clinical experimental research will diminish the amount of time for themselves and for their loved ones. Potentially so valuable, the dying process, may be severely disturbed. Again, this confronts us with the question whether experimental trials in palliative care can be conducted at all, without sacrifice of the patient's well-being.

2.3. Spiritual harms

The basis of every spirituality is hope (see chapter 6). Human beings cannot live without hope. This is true for everyone, for the dying as well as for the healthy. Patients with a fatal diagnosis continuously shift the object of their hope. Initially, all hope is directed at cure. Gradually, hope is directed at other objects: life prolongation, quality of life, the visit of a friend, a painless death, the presence of the patient's loved ones at the time of death. Hope provides meaning to the lives of terminal patients and in palliative care it ought to be sustained and fostered.

However, false hope, for example hope for cure when no cure can be achieved, can be torturing and a hindrance to a meaningful death. If patients, together with their loved ones, cling to their hope for a cure, they cannot at the same time prepare for farewell. Many patients engaging in phase I and II experimental studies perceive the information of the physician as a possible chance to cure, no matter how clear and univocal the physician's information is about the purpose of the experiment. These patients cling to life. Their hope is directed at cure which is clearly incompatible with the aim of the trial. This makes it much more difficult for patients and their relatives to accept imminent death. It would be hubris to state that acceptance of death is an aim of palliative care. For some patients, caregivers' attempts to make them accept their imminent death are inappropriate. Be that as it may, fostering a patient's hope for illusions is at odds with good palliative care practice. It may endanger the quality of a patient's dying process. Again, the conclusion that experimental treatment and total care for the dying are at odds with each other seems to force itself upon us.

3. An unsolvable dilemma?

In this paragraph, it will be indicated that the dilemma as described above does not *necessarily* have to occur. There is a way out. Principally, the intention of palliative care to achieve the best possible quality of life and participation in clinical trials do not have to be mutually exclusive. First, it will be indicated that the principle of autonomy, as it is understood in the liberal, minimalistic ethics, does not suffice in this respect as it cannot render an account of compassionate care. Thus, it is also unable to clarify why the dilemma does not necessarily have to occur. Recently, the principle of autonomy has been subject to re-interpretations, for example in the context of the ethics of care. However, instead of re-interpreting the principle of autonomy, the notion of authenticity, which was already analysed in chapter 6, will be proposed as an alternative. The notion of authenticity can, in contrast to the principle of autonomy, render account of the human freedom to choose on the one hand and of compassionate care on the other. Yet, the notion of authenticity alone is also insufficient. Situating it in the existentialist tradition (from which it originates) reveals that it cannot explain why we would have solidarity. This question (why have solidarity) is central to an ethical evaluation of clinical trials in palliative care and can be illuminated by pointing towards the notion of hope.

3.1. Autonomy

In the ninth paragraph of the Declaration of Helsinki IV, the requirement of informed consent for experimentation is explicitly stated (World Medical Association, 1989; Katz, 1992). Adequate information on the aims, methods, anticipated benefits, potential hazards and the discomfort of the study should be provided by the physician involved and patients should be free to abstain or withdraw from the study. The patient's autonomous consent is a demand for the permissibility of the research. In paragraph ten of the Declaration, it is stated that if the patient is in a dependent relationship with the physician, another physician, not engaged in the investigation, should obtain informed consent as to not make the patient consent under duress.

No one will deny the importance of these statements. Yet, the principle of autonomy does not solve our dilemma. As was analysed above, the principle was (re-)introduced in modern medical ethics in the late sixties. There, it developed as a cornerstone of a minimalist ethics which sought to protect the patients' interests against the newly established power of the physician. In a pluralistic society, patient and physician are moral strangers to each other. The doctor-patient relationship has become a contract. Trust is absent. Autonomy has thus become the reigning moral principle by default (Welie, 1998). If one accepts the presumptions of the modern liberal medical ethics, compassionate care is impossible. And if autonomy cannot render account of compassion, we would indeed be caught in an unsolvable dilemma between our societal duty to improve medical care for future patients (social justice) and nonmaleficence.

A second reason for the insufficiency of the principle of autonomy is that since the rise of modern medical ethics, autonomy has been part of a principlistic framework that primarily served to deduce moral guidelines instead of enhancing our understanding of moral practices. It is the latter that is the aim of this chapter.

An ethical evaluation of the use of clinical trials in palliative care requires a notion which on the one hand renders an account of the patient's freedom to choose and on the other hand renders an account of compassionate care; a notion, in other words, that has practical meaning for palliative care practice.

3.2. Authenticity

The notion of authenticity, as used in the existentialist philosophical tradition, renders an account of human freedom to choose on the one hand and of human vulnerability, dependency and fragility on the other hand (Welie, 1994). Both

aspects of authenticity have to be taken into account before considering it in the context of clinical trials in palliative care.

Human beings are thrown into existence. From the time of our birth on, we depend on what was already there before we were born. Our identity is shaped -for better or for worse- by numerous contingent factors beyond our control. However, we are not totally determined by these factors. After all, we can relate to them. We are able to transcend our conditionality by our freedom to choose and to carry on and shape traditions to which we belong. We fall ill, but we can relate to our illness. In fact, illness provides us with new options that would not have occurred had we not fallen ill. Between these options we have to make a choice and subsequently engage according to the choice we make. Authentic choices are choices in character. Whereas autonomous choices are present decisions which principally can be revised anytime, authentic choices are congruent with the personality of the subject as it has evolved in the past and as it stands open towards the future. Authentic choices fit the person who chooses. The autonomy of choices is assessed by its reasonability, the authenticity of choices is assessed by 'intimate knowledge', which has grown in the context of compassionate care for the patient and his or her loved ones.

The notion of authenticity can provide a meaningful perspective on the use of clinical trials in palliative care. Patients in palliative care are particularly vulnerable. They may feel obliged to participate in experimental research because of the optimal care they are receiving. Their perceived duty to do something in return for the team that has cared so well for them may be inauthentic. It is important to note that the dying are not necessarily more or less authentic than the healthy. Even though the dying are particularly vulnerable and dependent on the care of others, their authenticity does not necessarily have to diminish. First and foremost, they are equal living fellow human beings who, however, happen to be dying. Healthy persons are in their daily lives as authentic or inauthentic as dying patients. But since the dying are facing the end of their lives, a time which is for many a time of reconciliation with themselves and their loved ones, authenticity is of special value to them. In palliative care, authenticity should be sustained and fostered so that patients are given the room to make choices congruent with their innermost personality.

Acknowledging the fact that not only the dying are dependent and vulnerable but that we all are vulnerable and in need of care, may well create room for participation in a clinical trial. Thus, authenticity can render a better account for solidarity than autonomy can. "An invitation to a dying person to take part in a research project, even though it may not provide any benefit for himself, can create a good opportunity for contributing something of value to society as well

as achieving a degree of personal satisfaction" (Thorpe, 1992, p. 224). Engaging in an experimental clinical study out of solidarity with future patients can be an authentic choice, congruent with the personality of the patient. It may provide new meaning to the patient's life. The patient participates in favour of the community of which (s)he is a part. It creates the possibility for the dying person to keep a social role in a community that seems to evolve away from them.

Authenticity excludes momentaneous decisions discongruent with the patient's personality. For a choice to be authentic it should be made in character. At the same time, authenticity illuminates the dependency and vulnerability that we all share and can thus account for solidarity with future patients.

Not all patients receiving palliative care should be asked to participate in clinical trials. Authenticity does not require the patient to participate. All that needs to be shown here is that authenticity is a notion which is equipped to evaluate the use of clinical trials in palliative care.

However, in the existentialistic tradition, authenticity cannot adequately deal with ultimate questions of life and death which particularly force themselves upon the dying. In the philosophical tradition of existentialism, existence is all that is real. Without existence there is absolutely nothing. This idea clearly makes life absurd and fearsome in the face of death. Anxiety or absurdity as basic conditions of life seem hardly concordant with solidarity and compassion. Authenticity alone is not enough to solve the dilemma. In the end, it appears to be unable to answer the question why we should have solidarity.

3.3. Hope

Human life is finite. Therefore, ultimate questions concerning the meaning of life urge themselves upon us. In other words, our mortality requires an eschatology. Death forces us to give an ultimate meaning to life and thereby transcend the apparent absurdity and meaninglessness of life in the face of death. For some people, this ultimate meaning may remain implicitly present in the way they live their daily lives and in the things they deem important. Others have explicitly reflected on what they deem of central importance to their lives. But the answers we give to the ultimate questions of life, no matter how implicit, do provide all of us with hope. Without hope, we cannot live. The dying who suffer from the situation they are in and their loved ones who face bereavement cannot live without hope, no matter how small or how concealed it may sometimes appear. Together with authenticity, hope can be seen as a central notion in palliative care.

Hope is always connected to an object, something that is hoped for. As mentioned above, hope for illusory cures should not be sustained or fostered in

palliative care. For example, participation in a phase I or II trial as a way of beating the odds is potentially harmful for the patient and his or her relatives (Kodish and Post, 1995).

But of course, hope can also be directed at obtainable objects or events: a good quality of life, the visit of a friend, the presence of the dying's loved ones at the time of death, etc. This kind of hope is extremely important in palliative care and conditional for a meaningful life. It is this kind of hope that should be sustained and bolstered in palliative care.

In addition to hope for obtainable objects or events, hope can also transcend the immediately visible. Hope does not necessarily have to refer to obtainable objects. It can, for example, refer to personal fulfilment, knowing that absolute fulfilment cannot be obtained here and now. This hope often comes forth out of contrast experiences. It is a kind of hope that resists undeserved suffering. It does not deny the existence of suffering but it situates the suffering here and now in the larger perspective of a better future. The object of this 'eschatological hope' is what in the Christian tradition is called the Kingdom of God or 'Heaven on earth'. According to the German theologian Moltmann, hope is the grounding structure of life (Moltmann, 1966). Hope in the Christian tradition is ultimately aimed at the establishment of the Kingdom of God, not primarily in the afterlife but here and now, in the resistance to all human suffering.

This eschatological hope has been of central importance for the Christian tradition. Obviously, it does not only regard Christians but is of universal significance. And even though theologians may explain it by referring to notions that are not acceptable for everyone (e.g. Kingdom of God, Heaven on earth, etc.), these Christian notions can be translated into universal notions (e.g. personal fulfilment, resistance to suffering, solidarity etc.).

In the context of this chapter, hope can provide a meaningful perspective. Patients may, in the context of good care, be able to share in this hope. Their undeserved suffering and (premature) death can, without denying it, be situated in a hopeful perspective on a better future and hence acquire meaning. This hope not only renders an account of solidarity with future patients; what is more, solidarity and hope evoke each other. From the contrast experience of their suffering some patients may experience hope for a better future in which future patients can be treated better and will need to suffer less. Thus, participating in clinical trials may sustain and bolster hope for these patients (Sacred Congregation for the Doctrine of Faith, 1980). And as such, clinical trials can be part of palliative care.

Conclusion

The main question of this chapter was whether clinical trials can be compatible with palliative care. First, the origins of the problem have been sketched. Palliative care initially stepped out of mainstream medicine because of a moral discomfort with the routine care for the dying. Optimal care for the dying has always set the norm for palliative care practice. At first sight, experimental research seems at odds with palliative care as it potentially endangers the physical, psychosocial and spiritual well-being of the dying. However, upon closer observation this does not always have to be the case. Two moral notions have been proposed which both evoke each other and have the potential to bring together social justice (better treatment for future patients) and nonmaleficence (or what's more, compassionate care for the individual patient). The first notion is the notion of authenticity which renders account of the freedom of the patient to choose and of solidarity with future patients. Many dying patients can, in the context of compassionate care, make an authentic choice, a choice in character, to participate in a clinical trial. However, solidarity with future patients does not appear out of the blue and needs to be further explained. Authenticity alone is insufficient and needs to be paired with an eschatological perspective. This perspective can be provided by the notion of hope. Hope is foundational in palliative care because it is conditional for a meaningful life. Hope can be directed at obtainable objects but it can also be of an eschatological character. This eschatological hope refers to hope for a better future, a future in which patients can be better treated for their disease. For some patients, but not for all, this kind of hope may be fostered through participation in experimental research. An ethical use of clinical trials requires some selection, based on an intimate knowledge. Not all patients should be asked to participate. But some patients' lives may gain meaning by participation in clinical trials. If that is so, clinical trials can be part of palliative care.

Note

* Modifications in comparison to the published article:
In order to avoid overlap with chapter 6, a small number of sentences regarding the notions of hope and authenticity have been deleted.

CONCLUSION

PERSPECTIVES FOR PALLIATIVE CARE

CONCLUSION:

PERSPECTIVES FOR PALLIATIVE CARE

The conclusion of this thesis will focus on four future challenges that face palliative care in the nearby future. In the various studies of this research project, suggestions have been formulated and directions have been proposed to meet these challenges. Further research will be necessary to meet these challenges.

The first challenge regards the articulation of the specific set of values palliative care is said to entail. Since palliative care is increasingly organised in the context of a variety of medical practices, articulation of the moral aspects through which palliative care can be demarcated from other practices has become an urgent requirement. The findings that were discussed in chapters 2, 3 and 4 are relevant in this respect. Second, moral notions used in the debates on palliative care are in need of more thorough historical, philosophical and theological analysis if new enriching perspectives on palliative care practice are to emerge. Based on the theoretical methodology formulated in chapter 1, and based on the analyses of the moral notions that were discussed in chapters 5 and 6, future research needs to be carried out. Third, the debates on moral dilemmas in palliative care need to be broadened by addressing alternative palliative measures for euthanasia, and assessing what patients really mean when they request for euthanasia. At the same time, in the context of a pluralistic society, different opinions should be allowed to co-exist. Chapters 7, 8 and 9 intended to provide prolegomena for such debates. Finally, a wider issue of palliative care merits attention. This issue relates to current attitudes towards death and dying. It was marginally addressed in chapters 6 and 9. It is argued that the hospice movement and the subsequent development of palliative care have been both symptomatic and stimulative for a new attitude towards death and dying that is nowadays occurring in many Western countries. In the direct confrontation with death, many of us have learnt to acknowledge that death and dying provide us with potential to give and receive meaning in life. An increasing openness towards human mortality, allows meaningful perspectives on life to emerge.

1. Demarcation of palliative care from other medical practices

As we have discussed throughout the preceding chapters, palliative care has been subject to important changes in the last three decades. The identification of palliative care with hospice care, terminal care and cancer care can and should no longer be assumed. As was discussed in chapter 3, only a small minority of professionals working in the field of palliative care prefer to denote their profession as terminal care whereas a majority hold that palliative care starts from the time of diagnosis. Furthermore, the vast majority do no longer associate palliative care with the hospice institution but agree that palliative care should be fully integrated within the mainstream health care system. If we take the views of this majority seriously, it is safe to conclude that palliative care will in the nearby future increasingly be formed in the context of a variety of medical practices. Attention will be shifted to other groups of patients than those suffering from cancer. Patients suffering from diseases such as chronic heart failure, kidney disease, neurological disease (notably dementia) and chronic diseases such as multiple sclerosis, will be cared for by caregivers who affiliate themselves with palliative care. In order to meet the demands from the formal health care systems, research in palliative care will remain focused on the establishment of an evidence base, and the care provided will have to be cost-effective and efficient. Furthermore, the 'emotional planning' of the past, especially in the British context, will have to be abandoned and establishment of palliative care units will have to render account of the demand in a certain region (Clark et al, 1997). This process of integration is on the one hand a process of maturation of palliative care. As was indicated throughout the preceding chapters, this process was expected and aimed at by many hospice caregivers themselves. On the other hand, it will lead to an increasing ambiguity of the concept of palliative care. If palliative care forms a part of many medical practices, whether they be curative or palliative, how can we be able to demarcate the concept and practice of palliative care from these medical practices? The demarcation of palliative care is one of the major challenges palliative care faces at the beginning of the 21st century. Again, the majority hold that palliative care should be fully integrated with the mainstream health care system. But at the same time, concern is expressed about the medicalisation of palliative care (remarkably, much less concern is expressed about bureaucratisation). Integrating palliative care in a variety of medical practices carries with it the risk of medicalisation, i.e. the risk of loosing exactly that what is at the heart of palliative care, namely the quality of life of the patient and his or her loved ones from a physical, mental, social and spiritual point of view. The

concern that is expressed regarding the medicalisation of palliative care is corroborated by the view of the majority that palliative care entails a specific set of values, other than the mainstream health care system. That being so, demarcating palliative care from other medical practices is probably an ethical enterprise. The specificity of palliative care is then a moral specificity. Clues for articulating this moral specificity can be drawn from the questionnaire study, in which it was indicated that the notions of acceptance of human mortality, quality of life, human dignity and total care are considered essential.

The moral values underpinning palliative care are not static notions, valid once and for all. Rather, the moral values said to be essential for palliative care are subject to historical change. In the last three decades for instance, religious values have lost territory. In this respect, it is noteworthy that a notion such as 'sanctity of life' is not considered important by the majority. In other words, the traditional axiology of hospice has increasingly become subject to critique. Instead of presuming a clear-cut set of values and norms, arguments to sustain these values and norms are now required in the context of ethical debates in a pluralistic society. It is not unlikely that the values that are currently said to be central to palliative care will change in the future. Be that as it may, if the demarcation of palliative care from other medical practices is at least for an important part of a moral nature, it is imperative to carry out further research in the moral values underpinning palliative care. Thus, an important challenge palliative care faces in the nearby future is: to assess, analyse and evaluate the moral values that are specific for palliative care in order to demarcate palliative care from other medical practices.

2. Moral notions denoting palliative care

In palliative care journals, there is a significant interest in ethical issues (Hermsen and Ten Have, 2001). The majority of ethical articles comes from the medical profession. Only a small minority is written by professional ethicists. This can explain the relative absence of historical, philosophical and theological theory in the debates on palliative care. Another source of explanation relates to the conception of the dominant form of medical ethics itself, as was indicated in the first chapter.

Because of the relative absence of historical, philosophical and theological theory, moral notions used in the ethical debates are often insufficiently subjected to critical analysis. Their meaning is too often taken for granted. Notions that are used in the field of medical ethics in general, such as

autonomy, beneficence, quality of life, are often uncritically applied to the field of palliative care. However, the meaning of such notions in the context of palliative care is likely to amount to something different than is the case in the context of curative practices. Moreover, the meaning of notions that are often used to denote a certain specificity of palliative care practices, such as spirituality, acceptance of mortality, psychosocial care, is also lacking critical analysis.

The relative absence of history, philosophy and theology in the literature of palliative care is to be regretted since notions that are said to be essential for palliative care remain unclear. Moreover, without a certain critical distance from palliative care practice, new, richer perspectives on palliative care are unlikely to be developed. In other words, as was argued in chapter 1, in order to be practically relevant for palliative care practice, ethicists should adopt a critical distance to the dominant ethical discourses. The meaning attributed to moral notions in the ethical debates should be made explicit. Then, it may appear that this meaning denotes a particular understanding, reflective of a particular discourse. Other meanings reflective of other discourses of the past may have been forgotten and can be re-introduced in order to shed a new enriching light on the notions used. In the confrontation of the current meaning of notions with other meanings that the notions once carried, new and richer perspectives are allowed to emerge. In this thesis for instance, the notion of pain is analysed from a philosophical perspective. In confronting dominant ways of dealing with pain (e.g. medical treatment), with other, forgotten meanings (e.g. heroism, art, religion), broader perspectives that are relevant for medical practice emerge. Critical distance is also required to assess what remains unspoken. New notions, or even neologisms, can be proposed if they carry more practical relevance than others. In this thesis, the notion of authenticity is proposed as an alternative for autonomy. In chapters 6 and 9, the term eschatology is used referring to the questions of ultimate importance that force themselves upon us at the end of our lives. Whereas 'spirituality' has become more of a container notion, the notion of eschatology may be better equipped to denote what 'spiritual' care is in the end about. Again, it requires a theological or philosophical background to introduce such notions since they have been part of philosophical and theological discourses of the past in which they were given meaning and in which they were reflected upon.

History, philosophy and theology bring the particularity of current discourses to the surface. They remind us that other discourses are possible. Their practical relevance for palliative care practice is concerned with their potential to confront current, dominant meanings with other, forgotten

meanings. Thus, new perspectives emerge that can sensitise the moral experience of the caregivers. A second challenge facing palliative care in the nearby future is thus: to introduce historical, philosophical and theological analysis of moral notions in order to allow new perspectives to emerge that provide a richer understanding of the morality of palliative care practice.

3. Moral dilemmas in palliative care

Up until recently, the debate on euthanasia in the Netherlands has focused on data, procedures and assessment of articulated conditions under which euthanasia would be tolerable. In the context of increasing interest in palliative care, the euthanasia debate is now widening. More attention is given to the preventability of requests for euthanasia by means of good compassionate care from the time of diagnosis onwards. Physicians who consider euthanasia a means of last resort, to be carried out only in very exceptional circumstances, agree that a further development of palliative care is among other (perhaps more important) reasons imperative in order to decrease the number of cases of euthanasia in the Netherlands.

As was pointed out in chapter 7, many patients assess at the time of admittance to a palliative care unit whether the physician is willing to carry out euthanasia on them if their suffering becomes unbearable. An affirmative answer from the physician, or a guarantee that they will not need to suffer unbearably, provides them with a feeling of security. Only a minority explicitly reiterate their request for euthanasia in a later stage of their illness. Many of them will meet the conditions that have been formulated in the Dutch jurisprudence. Indeed, their suffering may be unbearable in the physician's perception and their request may be autonomous. Meeting their request will not lead to prosecution of the physician. The assumption in those cases is (1) that the patient wants to die, and (2) that the patient wants to die from euthanasia, i.e. the patient wants to have his or her life actively ended. Caregivers in the field of palliative care are right to consider both assumptions problematic. Regarding the first assumption, the question why the patient wants to die should be addressed. Where does his or her suffering come from? Is the suffering of the patient refractory and can nothing be done anymore to relieve it? As it appears from the participant observation study in a Dutch hospice, reported in chapter 7, a patient's wish to die is often a cry for help. In the context of good interdisciplinary care, the wish to die often disappears. Regarding the second assumption, it is argued in chapter 8 that alternative palliative modalities are in

almost all cases available. Withdrawal of life prolonging treatment may in some cases be a satisfactory option for the patient. In a small minority of cases, terminal sedation may be the only alternative means of last resort to relieve the suffering of the patient. If we assume that the active taking of another person's life is at least *prima facie* morally wrong, and if we assume that intentions are relevant for the morality of our actions, terminal sedation is a morally better option than euthanasia. Some patients do want to die since their suffering is unbearable and refractory. But what is imperative in this respect is that these patients are presented with the possibility of more than one choice. Some may not prefer to be killed by the physician who has cared for them. Instead, terminal sedation may be a preferable option for these patients. Others may hold on to their request to have their lives actively ended. These are difficult cases in which the autonomy of the patient can never be the only and exclusive argument to meet the request because the autonomy of the physician is as important. The issue of terminal sedation has so far been left largely unaddressed in the Dutch debate. Even though empirical evidence is hard to find, it seems as if in the Netherlands the unproven assumption prevails that active euthanasia is a more comfortable way of dying than dying in a state of sleep.

Throughout the thesis, it has been argued that the traditional axiology of the hospice concept is increasingly subject to debate. It is more and more acknowledged that normative statements require arguments to justify them. For a long time however, caregivers in palliative care outside the Netherlands have relied on firm statements against euthanasia, either arguing that the option of euthanasia decreases the quality of palliative care or arguing that the option of euthanasia is necessitated because of a poor quality of palliative care. Both arguments are problematic if one oversees recent developments in the Netherlands. As was pointed out in chapter 2, a critical, open debate on the (im)morality of euthanasia as well as on the traditional axiology of the hospice concept should be the goal.

There are many more moral dilemmas in palliative care practice. Not only medical decisions such as withholding or withdrawing medical treatment, use of high doses pain medication, status of artificial hydration and research issues merit attention. Also moral problems in everyday practice, such as caring for difficult patients, the role of proxies, dealing with burn out, care for caregivers, need to be researched. The dilemmas addressed in this thesis dealt with medical decision-making issues at the end of life. It has to be acknowledged that moral problems of a different nature probably occur more often in everyday practice.

Based on what has been said about medical decision-making at the end of life, the third challenge for palliative care in the nearby future is: To broaden the

debates on euthanasia, stressing alternative palliative measures and assessing carefully what patients really mean when they request for euthanasia, while at the same time allowing for an open, critical debate on moral dilemmas in palliative care in which different opinions can co-exist.

4. Palliative care and human mortality

An issue that has marginally been addressed in chapters 2 and 6 relates to current attitudes towards death and dying. In 1974, 7 years after the opening of St Christopher's, Ariès argued that the western attitude towards death is characterised by denial. Death has become fearsome, forbidden, hidden away, and intolerable. Whereas death in earlier times took place in the home of the dying, death has now become more and more a medical enterprise, taking place in the context of hospitals. Often, medical decisions precede and influence the time of death. The physician, and not the priest or the dying person's loved ones, has become the director of his or her patient's death. The denial of death is thus closely related to the medicalisation of death (Ariès, 1974; Dekkers, 1995).

Articulating our West European attitude towards death at the end of the 20th century is problematic for two reasons. First, important varieties exist among the West European nations. Attitudes towards death in Spain differ considerably from attitudes in Northern European countries (Núñez Olarte and Gracia, 1999). Second, it seems as if different attitudes towards death are co-existent. On the one hand, it can be argued that death is disregarded (not necessarily denied) in the context of our everyday life. Living life constantly in the face of death makes our everyday concerns appear meaningless and absurd. Disregarding our mortality is necessary in order to be able to give meaning to our everyday concerns. On the other hand, it can be argued that in the direct confrontation with a dying loved one, our attitude is under change. As in earlier times, death is again becoming situated in the home of the dying. It is acknowledged that a time comes when life prolonging measures should be deemed futile. Unlike the time in which Ariès wrote his book, it is now agreed upon that the dying person has a right to know that he or she is dying. Death is again communicated. Funeral rites are given more and more attention. Personal elements, reflective of the deceased, are introduced (Dekkers, 1995). What is important in this respect is that the hospice movement and the subsequent developments in palliative care have been both symptomatic and stimulative for this change. Development of home care services, development of bereavement

services, rejection of the 'conspiracy of silence', refraining from disproportionate measures, have been central to hospice from the beginning.

It has been argued in chapters 6 and 9 that it is our mortality that makes an eschatology possible. Because we are mortal, we cannot escape from answering the questions that are of ultimate importance. Especially in the direct confrontation with our own or a loved one's death, we are confronted with these questions. In such situations, it appears that for many involved their main concern does not relate to themselves but to their loved ones (Desmet, 1996). Research among men that were cured from testicular cancer revealed that they viewed their lives more purposefully, they were capable of more enriching social relationships and their interest in personal ambition had decreased (Brodsky, 1995; Cited from Clark and Seymour, 1999).

We disregard death in our everyday lives because death makes our practical concerns look meaningless. Yet, many of us are not embarrassed in the direct confrontation with death. Instead, and paradoxical to what has been said, this confrontation provides us with potential to spiritually grow and receive meaning. The old maxim *memento mori* can sometimes help us realise what life is in the end about. The fourth challenge for palliative care in the nearby future is: to further stimulate new ways of dealing with death and dying, acknowledging that it is our mortality that enables us to give and receive meaning in life.

Of course, many more challenges that have not been addressed here face palliative care in the future. Improvement of care remains imperative. Education in palliative care in the medical and nursing curricula has been underestimated in many countries for too long. Further integration of palliative care will undoubtedly lead to competition struggles within which palliative care has to prove its effectiveness and efficiency.

In the beginning of the 21st century, the climate for progress in palliative care is favourable. In order to meet the positive challenges that lie ahead it is imperative that palliative care further reflects on an identity of its own. This thesis intends to contribute to this reflection.

References:

Ahmedzai S, The medicalization of dying. In: Clark D (ed.), *The future for palliative care. Issues of policy and practice.* Buckingham: Open University Press; 1993: 140-147.

Andrews M, Bell E, Smith S, Tischler J, Veglia J, Dehydration in terminally ill patients. Is it appropriate palliative care? *Postgraduate Medicine* 1993; 93: 201-206.

Angell M, The Supreme Court and physician-assisted suicide. The ultimate right. *New England Journal of Medicine* 1997; 336: 50-53.

Ariès P, *Western attitudes towards death. From the Middle Ages to the present.* Baltimore: Johns Hopkins University Press; 1974.

Aristotle, *The Nicomachean ethics.* Cambridge: Harvard University Press; 1961.

Árnason V, Towards authentic conversations. *Theoretical Medicine* 1994; 15: 227-242.

Ashby M, Stoffell B, Therapeutic ratio and defined phases. Proposal for an ethical framework of palliative care. *British Medical Journal* 1991; 302: 1322-1324.

Ashby M, Stoffell B, Artificial hydration and alimentation at the end of life. A reply to Craig. *Journal of Medical Ethics* 1995; 21: 135-140.

Baar FPM, *Lessen van Levenden. 20 jaar palliatieve en terminale zorg in Antonius Ijsselmonde.* Rotterdam: Antonius Ysselmonde; 1998.

Beauchamp TL, Childress JF, *Principles of biomedical ethics.* New York: Oxford University Press; 1994 (fourth edition).

Beecher HK, Ethics in clinical research. *New England Journal of Medicine* 1966; 274: 1354-1360.

Biesenbeek FJ, Overheidsbeleid en terminale zorg. In: Project Antonius Ysselmonde. *Omgaan met sterven deel IV. Symposiumverslagen.* Leiden: Zorn; 1985: 5-19.

Billings JA, Block SD, Slow euthanasia. *Journal of Palliative Care* 1996; 12: 21-30.

Blackledge G, Lawton FF, The ethics and practical problems of phase I and II studies. In: Williams CJ (ed.), *Introducing new treatments for cancer. Practical, ethical and legal problems.* Chichester: John Wiley and Sons; 1992: 137-148.

Boff C, *Theologie und Praxis. Die erkenntnistheoretischen Grundlagen der Theologie der Befreiung.* München: Kaiser; 1983.

Boisvert M, All things considered ... then what? *Journal of Palliative Care* 1988; 4: 115-118.

Boyle JM, Toward understanding the principle of double effect. *Ethics* 1980; 90: 527-538.

Boyle J, Who is entitled to double effect? *Journal of Medicine and Philosophy* 1991; 16: 475-494.

Bradshaw A, The spiritual dimension of hospice. The secularization of an ideal. *Social Science and Medicine* 1996; 43: 409-419.

Brandt E, Dokter met de handen op de rug. Interview with B. Zylicz. *Trouw* (Dutch newspaper), 16th April 1999.

Brodsky MS, Testicular cancer survivors' impressions of the impact of the disease on their lives. *Qualitative Health Research* 1995; 5: 78-96.

Brody H, Causing, intending, and assisting death. *Journal of Clinical Ethics* 1993; 4: 112-117.

Brody H, Campbell M, Faber-Langendoen K, Ogle K, Withdrawing intensive life-sustaining treatment. Recommendations for compassionate clinical management. *New England Journal of Medicine* 1997; 336: 652-657.

Broeckaert B, Le cure palliative in Belgio. *Bioetica e Cultura* 1999; 8: 45-54.

Bruning H, Klein Hesselink J, Conclusies en suggesties van het projekt Antonius-Ysselmonde. In: Project Antonius Ysselmonde. *Omgaan met sterven deel IV. Symposium-verslagen.* Leiden: Zorn; 1985: 102-141.

Bruntink R, Vooral de thuiszorg moet zich gaan ontwikkelen. Interview with G. van den Berg. *Pallium* 1999a; 1: 14-15.

Bruntink R, Editorial. Stammenstrijd. *Pallium* 1999b; 1: 2.

Bruntink R, Verpleeghuizen profileren zich op palliatieve zorg. Interview with F. Baar. *Pallium* 1999c; 1: 9-13.

Bruntink R, Het ene hospice is het andere niet. Citation from C. Kenter. *Pallium* 1999d; 1: 7-10.

Burt RA, The Supreme Court speaks. Not assisted suicide but a constitutional right to palliative care. *New England Journal of Medicine* 1997; 337: 1234-1236.

Buytendijk FJJ, *Over de pijn.* Utrecht: Het Spectrum; 1943.

Byock IR, Consciously walking the fine line. Thoughts on a hospice response to assisted suicide and euthanasia. *Journal of Palliative Care* 1993; 9: 25-28.

Calman KC, Hanks GWC, Clinical and health services research in palliative care. In: Doyle D, Hanks GWC, MacDonald N (eds.), *The Oxford Textbook of Palliative Medicine*. Oxford: Oxford University Press; 1993: 73-77.

Campbell CS, Hare J, Matthews P, Conflicts of conscience. Hospice and assisted suicide. *Hastings Centre Report* 1995; 25: 36-43.

Campbell N, A problem for the idea of voluntary euthanasia. *Journal of Medical Ethics* 1999; 25: 242-244.

Cavanaugh TA, The ethics of death-hastening and death-causing palliative analgesic administration to the terminally ill. *Journal of Pain and Symptom Management* 1996; 12: 248-254.

Chater S, Viola R, Paterson J, Jarvis V, Sedation for intractable distress in the dying. A survey of experts. *Palliative Medicine* 1998; 12: 255-269.

Cherny NI, Coyle N, Foley K, The treatment of suffering when patients request elective death. *Journal of Pain and Symptom Management* 1994; 10: 71-79.

Cherny NI, Portenoy RK, Sedation in the management of refractory symptoms. Guidelines for evaluation and treatment. *Journal of Palliative Care* 1994; 10: 31-38.

Cherny N, Commentary. Sedation in response to refractory existential distress. Walking the fine line. *Journal of Pain and Symptom Management* 1998: 16; 404-406.

Chochinov HM, Wilson KG, The euthanasia debate. Attitudes, practices and psychiatric considerations. *Canadian Journal of Psychiatry* 1995; 40: 593-601.

Clark D, Someone to watch over me. *Nursing Times* 1997; 93: 50-52.

Clark D, Originating a movement. Cicely Saunders and the development of St Christopher's Hospice, 1957-1967. *Mortality* 1998; 3: 43-63.

Clark D, Seymour J, *Reflections on palliative care*. Buckingham: Open University Press; 1999.

Clark D, Le cure palliative nel Regno Unito. *Bioetica e Cultura* 1999; 8: 155-162.

Clark D, ten Have HAMJ, Janssens MJPA, Common threads? Palliative care service developments in seven European countries. *Palliative Medicine* 2000; 14: 479-490.

Clark D, Palliative care history. A ritual process? *European Journal of Palliative Care* 2000; 7(2): 50-55.

Coene RD, 'Hospice-zorg' nader bekeken. Terminale zorg is geen categorale zorg. *Medisch Contact* 1991; 39: 1156-1158.

Craig GM, On withholding nutrition and hydration in the terminally ill. Has palliative medicine gone too far? *Journal of Medical Ethics* 1994; 20: 139-143.

Craig GM, On withholding artificial hydration and nutrition from the terminally ill. The debate continues. *Journal of Medical Ethics* 1996; 22: 147-153.

Crul BJP, Pijnbestrijding bij kanker. Een stiefkind van de geneeskunde. *Medisch Contact* 1981; 5: 127-129.

Crul BJP, *Mens en pijn. Achtergronden en mogelijkheden van pijnbestrijding.* Nijmegen: Valkhof Pers; 1999.

Crul BJP, Pijnbestrijding in de laatste levensfase. *Nederlands Tijdschrift voor Geneeskunde* 1997; 141: 2097-2100.

Danhoff E, Met palliatieve zorg kun je drie, vier jaar voor de dood al beginnen. Interview with Martin Smalbrugge. *Pallium* 1999; 1: 11-13.

De Grijs FJA, *Goddelijk mensontwerp.* Hilversum: Paul Brand; 1967.

Demmer K, *Leben in Menschenhand. Grundlagen der bioethische Gesprächs.* Freiburg: Herder; 1987.

Demmer K, Das Selbstverständnis der Moraltheologie. In: Ernst W (ed.), *Grundlagen und Probleme der heutigen Moraltheologie.* Würzburg: Echter; 1989: 9-25.

Dekkers WJM, *Het bezielde lichaam. Het ontwerp van een antropologische fysiologie en geneeskunde volgens F. J. J Buytendijk.* Zeist: Kerckebosch; 1985.

Dekkers WJM, What do we call death? Some reflections on the end of life in western culture. *Ethical Perspectives* 1995; 2(4): 188-197.

Desmet M, *Dag en nacht. Een spiritualiteit van de medische ervaring.* Tielt: Lannoo; 1996.

Donagan A, Moral absolutism and the double-effect exception. Reflections on Joseph Boyle's who is entitled to the double effect? *Journal of Medicine and Philosophy* 1991; 16: 495-509.

Dorrepaal K, *Pijn bij patiënten met kanker.* Meppel: Krips Repro; 1989.

Doyle D, Palliative medicine. A time for definition? *Palliative Medicine* 1993; 7: 253-255.

Doyle D, Hanks GWC, MacDonald N, Introduction. In: Doyle D, Hanks GWC, MacDonald N (eds.), *Oxford Textbook of Palliative Medicine.* Oxford: Oxford University Press; 1996: 3-8.

Dunlop RJ, Ellershaw JE, Baines MJ, Sykes N, Saunders CM, On withholding nutrition and hydration in the terminally ill. Has palliative medicine gone too far? A reply. *Journal of Medical Ethics* 1995; 21: 135-140.

Dupuis HM, Thung PJ, *Voordelen van de twijfel. Een inleiding tot de gezondheidsethiek.* Alphen aan de Rijn: Stafleu; 1988.

Dutch Health Council, *Pijn en pijnbehandeling.* Den Haag: Gezondheidsraad; 1986.

Dutch Parliament, *Wet toetsing levensbeëindiging op verzoek en hulp bij zelfdoding.* Text nr. 26691, 1998-1999.

Dutch Parliament, *Kabinetsstandpunt n.a.v. de evaluatie van de meldingsprocedure euthanasie.* Text nr. 23877, 1997.

Elfrink E, Brede definitie palliatieve zorg komt duidelijkheid niet ten goede. *Pallium* 1999; 1: 15-16.

Ellershaw JE, Sutcliffe JM, Saunders CM, Dehydration and the dying patient. *Journal of Pain and Symptom Management* 1995; 10: 192-197.

Emanuel EJ, Daniels ER, Fairclough DL, Clarridge BR, The practice of euthanasia and physician-assisted suicide in the United States. Adherence to proposed safeguards and effects on physicians. *Journal of the American Medical Association* 1998; 280: 507-513.

Engelhardt HT, *Bioethics and secular humanism: The search for a common morality.* London: Trinity Press International; 1991.

Enklaar J, *Terminus. Dr. Ben Zylicz en de kunst van het sterven.* Zutphen: Plataan; 1999.

Farsides C, Autonomy and its implications for palliative care. A Northern European perspective. *Palliative Medicine* 1998; 12: 147-151.

Field D, Palliative medicine and the medicalization of death. *European Journal of Cancer Care* 1994; 3: 58-62.

Foley KM, Competent care for the dying instead of physician-assisted suicide. *New England Journal of Medicine* 1997; 336: 54-58.

Gadamer HG, *Warheit und Methode.* Tübingen: Mohr; 1975.

Gaudium et Spes. Pastoral Consitution on the Church in the Modern World. Second Vatican Congress, 1967.

Goldin G, A protohospice at the turn of the century. St Luke's house, London, from 1893 to 1921. *Journal of the History of Medicine and Allied Sciences* 1981; 4: 383-415.

Gordijn B, *Die Person und die Unbestimmbarkeit ihrer Grenzen. Eine grundlegende Kritik an der Debatte über Personenidentität.* Frankfurt am Main: Peter Lang; 1996.

Gordijn B, Janssens MJPA, The prevention of euthanasia through palliative care. New developments in the Netherlands. *Patient Education and Counselling* 2000; 41: 35-46.

Government Committee on Choices in Health Care, *Choices in health care.* Rijswijk: Ministry of Welfare, Health and Cultural Affairs; 1992.

Gracia D, Núñez Olarte JM, Le cure palliative in Spagna. *Bioetica e Cultura* 1999; 8: 163-172.

Groen JJ, Het syndroom van de onbehandelbare pijn. *Nederlands Tijdschrift voor Geneeskunde* 1979; 123: 374-379.

Hamel R, Lysaught T, Choosing palliative care. Do religious beliefs make a difference? *Journal of Palliative Care* 1994; 10: 61-66.

Hauerwas S, *The peaceable kingdom. A primer in Christian ethics.* Notre Dame: University of Notre Dame Press; 1983.

Heidegger M, *Sein und Zeit.* Tübingen: Niemeyer; 1986.

Hendin H, Rutenfrans C, Zylicz Z, Physician assisted suicide and euthanasia in the Netherlands. Lessons from the Dutch. *Journal of the American Medical Association* 1997; 277: 1720-1722.

Hermsen MA, ten Have HAMJ, Moral problems in palliative care journals. *Palliative Medicine* 2001 (in press).

Holdener EE, Decoster G, Lim CM, Ethical aspects of phase I studies in cancer patients. In: Williams CJ (ed.), *Introducing new treatments for cancer. Practical, ethical and legal problems.* Chichester; John Wiley and Sons; 1992: 149-159.

Humphreys C, *Undying spirits. Religion, medicine and institutionalised care of the dying, 1878-1938.* PhD thesis: University of Sheffield; 2000.

Illhardt F-J, Le cure palliative in Germania. *Bioetica e Cultura* 1999; 8: 173-180.

Inturissi CE, Opioid analgesics for cancer pain. In: Foley K, Bonica JJ, Ventafridda V (eds.), *Advances in pain research and therapy, vol 16.* New York: Raven; 1990: 133-154

James N, Field D, The routinization of hospice. Charisma and bureaucratization. *Social Science and Medicine* 1992; 34: 1363-1375.

James V, Field D, Who has the power? Some problems and issues affecting the nursing care of dying patients. *European Journal of Cancer Care* 1996; 5: 73-80.

Janssens MJPA, Lippendienst aan palliatieve zorg. *Trouw* (Dutch newspaper), 28th March, 1997.

Janssens MJPA, ten Have HAMJ, Le cure palliative in Olanda. *Bioetica e Cultura* 1999; 8: 23-32.

Janssens MJPA, Gordijn B, Palliativmedizin in den Niederlanden. *Deutsche Medizinische Wochenschrift* 1998; 123: 432-435.

Janssens MJPA, ten Have HAMJ, Zylicz Z, Hospice and euthanasia in the Netherlands. An ethical point of view. *Journal of Medical Ethics* 1999; 25: 408-412.

Jennings B, Active euthanasia and forgoing life-sustaining treatment. Can we hold the line? *Journal of Pain and Symptom Management* 1991; 6: 312-316.

Jochemsen H, Redactioneel (1). Reactie wetsvoorstel levensbeëindigend handelen. *In Perspectief* 1999; 12: 3-5.

Kant I, *Religion innerhalb der Grenzen der blossen Vernunft.* Hamburg: Meiner; 1956.

Kant I, *Kritik der praktischen Vernunft.* Stuttgart: Reclam; 1978.

Kant I, *Der Streit der Fakultäten.* Hamburg: Meiner; 1959.

Katz J, The consent principle of the Nuremberg Code. Its significance then and now. In: Annas GJ, Grodin MA (eds.), *The Nazi doctors and the Nuremberg Code. Human rights in human experimentation.* Oxford: Oxford University Press; 1992: 227-239.

Keizer B, Het regent in die hospices morfine. *Trouw* (Dutch newspaper): April 22, 1999.

Kerr D, Mother Mary Aikenhead, the Irish Sisters of Charity and Our Lady's Hospice for the Dying. *The American Journal of Hospice and Palliative Care* 1993; 3: 13-20.

Kirschner J, *Die Hospizbewegung in Deutschland am Beispiel Recklinghausen.* Frankfurt am Main: Peter Lang; 1996.

Kodish E, Post SG, Oncology and hope. *Journal of Clinical Oncology* 1995; 13: 1817-1822.

Kübler-Ross E, *On death and dying.* London: Collier-Macmillan; 1969.

Kuitert HM, Morele consensus. Mogelijkheden en grenzen. In: De Beaufort ID, Dupuis HM (eds.), *Handboek Gezondheidsethiek.* Assen: Van Gorcum; 1988: 29-40.

MacIntyre A, *After virtue. A study in moral theory.* Notre Dame: University of Notre Dame Press; 1984.

Manschot H, Kwetsbare autonomie? Over afhankelijkheid en onafhankelijkheid in de ethiek van zorg. In: Manschot H, Verkerk M (eds.), *Ethiek van de zorg. Een discussie.* Amsterdam: Boom; 1994: 97-118.

Max MB, Portenoy RK, Pain research. Designing clinical trials in palliative care. In: Doyle D, Hanks GWC, MacDonald N (eds.), *Oxford Textbook on Palliative Medicine.* Oxford: Oxford University Press; 1993: 77-86.

McQuay H, Moore A, Need for rigorous assessment of palliative care. Although difficult, randomised trials are mandatory. *British Medical Journal* 1994; 309: 1315-1316.

McWhinney IR, Bass MJ, Donner A, Evaluation of a palliative care service. Problems and pitfalls. *British Medical Journal* 1994: 309: 1340-1342.

Menges LJ, *Over pijn gesproken.* Kampen: Kok; 1992.

Merks KW, Van publieke betekenis. Theologie in een geseculariseerde samenleving. In: Houdijk MJ, Pieper J (eds.), *Dienst aan mensen. Opstellen aangeboden aan Harry Spee ss.cc.* Baarn: Gooi en Sticht; 1995: 202-221.

Metz W, *Het verschijnsel pijn. Methode en mensbeeld van de geneeskunde.* Haarlem: Erven F. Bohn; 1964.

Metz W, *Pijn. Een teer punt.* Nijkerk: Callenbach; 1975.

Metz W, Pijnlijders. *Wijsgerig Perspectief* 1997/1998; 38: 41-47.

Mieth D, Traktat über angewandte Ethik. From the unpublished course of the Nijmegen Centre for Ethics: *Erfahrung und Begründung des sittlich Richtigen am Beispiel bioethischer Probleme.* Nijmegen 1996, page 9-119.

Mill JS, *On liberty.* New York: Norton; 1975.

Miller FG, The good death, virtue, and physician-assisted death. An examination of the hospice way of death. *Cambridge Quarterly of Health Care Ethics* 1995; 4: 92-97.

Ministerie van Volksgezondheid, Welzijn en Sport, *Palliatieve zorg in de terminale fase. Brief aan de Voorzitter van de Tweede Kamer der Staten Generaal.* 18 April, 1996.

Moltmann J, *Theologie der Hoffnung. Untersuchungen zur Begründung und zu den Konsequenzen einer christlichen Eschatologie.* München: Kaiser Verlag; 1966.

Morita T, Satoshi I, Satoshi C, Sedation for symptom control in Japan. The importance of intermittent use and communication with family members. *Journal of Pain and Symptom Management* 1996; 12: 32-38.

Mount B, Morphine drips, terminal sedation, and slow euthanasia. Definitions and facts, not anecdotes. *Journal of Palliative Care* 1996; 12: 31-37.

Murray Parkes C, Bereavement. In: Doyle D, Hanks GWC, MacDonald N, eds. *The Oxford Textbook of Palliative Medicine.* Oxford: Oxford University Press; 1996: 663-679.

NVVz, *Verpleeghuizen in de keten van palliatieve terminale zorg.* Utrecht: Nederlandse Vereniging voor Verpleeghuiszorg; 1998.

NIVEL, *Palliatieve zorg in Nederland.* Utrecht: NIVEL; 1997.

NPTN, *Reader on the development of palliative care, an inventory of current projects and background information on its membership.* Unpublished: 1997.

O'Connor M, Palliative care and the euthanasia debate in Australia. *European Journal of Palliative Care* 1998; 5: 27-31.

Orentlicher D, The Supreme Court and physician-assisted suicide. Rejecting assisted suicide but embracing euthanasia. *New England Journal of Medicine* 1997; 337: 1236-1239.

Osuna E, The right to information for the terminally ill patient. *Journal of Medical Ethics* 1998; 24: 106-109.

Pappworth MH, *Human guinea pigs.* London: Routledge; 1967.

Pellegrino ED, Thomasma DC. *A philosophical basis of medical practice. Toward a philosophy and ethic of the healing profession.* Oxford: Oxford University Press; 1981.

Phipps WE, The origin of hospices/hospitals. *Death studies* 1988; 12: 91-99.

Pijnenburg M, Marginalisering van zieken en zorgbehoevenden. In: Houdijk MJ (ed.), *Theologie en marginalisering. Ethiek en theologie vanuit de marge.* Baarn: Gooi en Sticht; 1992: 111-126.

Pope John Paul II, Catholic Doctors. Higher witnesses. In: *The pope speaks.* 1983; 1: 30-35. Cited from: O'Rourke K, Boyle P (eds.), *Medical ethics. Sources of Catholic teachings.* Washington: Georgetown University Press; 1993: 191.

Portenoy R, Morphine infusions at the end of life. The pitfalls of reasoning from anecdote. *Journal of Palliative Care* 1996; 12: 44-46.

Privitera S, Accezioni semantiche e prassi medica in Italia. In: Privitera S (ed.), *Vivere bene nonostante tutto. Le cure palliative in Europa e in Italia.* Acireale: Ed. ISB; 1999: 117-140.

Quartier T, *Mit dem Tod leben. Philosophische Überlegungen zu Leben und Tod anhand von Sören Kierkegaard.* Nijmegen: Philosophical Faculty KU Nijmegen; 1998.

Quartier T, *Mein Gott, mein Gott, warum hast du mich verlassen? Die religiöse Bedeutung des Katholischen Bestattungsritus für Hinterbliebene.* Nijmegen: Theological Faculty KU Nijmegen; 1999.

Quill TE, Death and dignity. A case of individualized decision making. *New England Journal of Medicine* 1991; 324: 691-694.

Quill TE, Palliative options of last resort. A comparison of voluntarily stopping eating and drinking, terminal sedation, physician-assisted suicide, and voluntary euthanasia. *Journal of the American Medical Association* 1997; 278: 2099-2104.

Quill TE, Byock IR, Responding to intractable terminal suffering. The role of terminal sedation and voluntary refusal of food and fluids. *Annals of Internal Medicine* 2000; 132: 408-414.

Randall F, Downie RS, *Palliative care ethics. A good companion.* Oxford: Oxford Medical Publications; 1996.

Reith N, Intensieve zorg aan huis. `Steeds meer huisartsen durven het aan de patiënt naar huis te laten gaan'. *Pallium* 1999; 1: 7-10.

Rey R, *The history of pain.* Paris: Éditions la Découverte; 1993.

Ricoeur P, Life in quest of narrative. In: Wood D (ed.), *On Paul Ricoeur. Narratives and interpretation.* London: Routledge; 1991: 20-33.

Robbins M, *Evaluating palliative care services. Establishing the evidence base.* Oxford: Oxford University Press; 1998.

Rosen EJ, Commentary. A case of 'terminal sedation' in the family. *Journal of Pain and Symptom Management* 1998; 16; 406-407.

Rothman DJ, *Strangers at the bedside. A history of how law and bioethics transformed medical decision making.* New York: Basic Books; 1991.

Ruthenfrans C, Versterving is in strijd met eisen van zorgvuldigheid. *Volkskrant* (Dutch newspaper): August 7, 1997.

Sacred Congregation for the Doctrine of the Faith, *Declaration on Euthanasia.* Vatican City: Vatican Press; 1980.

Sahm S, Palliative care versus euthanasia. The German position: The German General Medical Council's principles for medical care of the terminally ill. *Journal of Medicine and Philosophy* 2000; 25: 195-219.

Sartre J-P, *L'être et le néant. Essai d'ontologie phénoménologique.* Paris: Gallimard; 1944.

Saunders C, Hospice care. *American Journal of Medicine* 1978; 65: 726-728.

Saunders C, Care of the dying. *Nursing Times.* 1960; supplement.

Saunders C, *The management of terminal illness.* London: Hospital Medicine Publications; 1967.

Saunders C, Foreword. In: Doyle D, Hanks GWC, MacDonald N (eds.), *Oxford Textbook of Palliative Medicine.* Oxford: Oxford University Press; 1996; V – VIII.

Saunders C, Past present and future hospice and palliative care. *History of Nursing Journal* 1994a; 5: 43-45.

Saunders C, The dying patient. In: Gillon R (ed.), *Principles of health care ethics.* Chichester: Wiley; 1994b: 775-782.

Saunders C, Summers D, Teller N, *Hospice. The living idea.* Leeds: Edward Arnold; 1981.

Schotsmans P, *De maakbare mens.* Leuven: Acco; 1994.

Schotsmans P, Palliatieve zorg als totale zorg aan terminale patiënten. *Acta Hospitalia* 1995; 35: 5-17.

Scott PA, Autonomy, power, and control in palliative care. *Cambridge Quarterly of Healthcare Ethics* 1999; 8: 139-147.

Singer PA, *Practical ethics.* New York: Cambridge University Press; 1993.

Skinner B, One patient looks at cancer. In: Stoll BA (ed.), *Coping with cancer stress.* Dordrecht: Nijhoff; 1986: 175-185.

Smith II GP, Restructuring the principle of medical futility. *Journal of Palliative Care* 1995; 11: 9-16.

SICP (Società Italiana di Cure Palliative), *Realtà existenti e operanti in Italia nel campo delle cure palliative.* SICP: Milan; 1995.

Sporken CP, *Begeleiding en ethiek. Verantwoordelijkheid en solidariteit van de hulpverlener.* Baarn: Ambo; 1983.

Stone P, Phillips C, Spruyt O, Waight C, A comparison of the use of sedatives in a hospital support team and in a hospice. *Palliative Medicine* 1997; 11: 140-141.

Stout J, *Ethics after Babel. The language of morals and their discontents.* Boston: Beacon; 1988.

Sulmasy DP, Pellegrino ED, The rule of double effect. Clearing up the double talk. *Archives of Internal Medicine* 1999; 159: 545-550.

Taylor C, *The ethics of authenticity.* Cambridge: Harvard University Press; 1992.

Ten Have HAMJ, The hyperreality of clinical ethics. A unitary theory and hermeneutics. *Theoretical Medicine* 1994; 15: 113-131.

Ten Have HAMJ, The anthropological tradition in the philosophy of medicine. *Theoretical Medicine* 1995; 16: 3-14.

Ten Have HAMJ, Janssens MJPA, Regulating euthanasia in the Netherlands. Ethics committees for review of euthanasia? *HEC Forum* 1997; 9: 393-399.

Ten Have HAMJ, Kimsma GK, *Geneeskunde tussen droom en drama. Voortplanting, ethiek en vooruitgang.* Kampen: Kok Agora; 1987.

Ten Have HAMJ, Lelie A, Medical ethics research between theory and practice. *Theoretical Medicine* 1998; 19: 263-276.

Ten Have HAMJ, Welie JVM, Euthanasia in the Netherlands. *Critical Care Clinics* 1996; 12: 97-108.

Thomas Aquinas, *Quaestiones Disputatae de Anima.* Rome: Éditions du Cerf; 1996.

Thorns A, A review of the doctrine of double effect. *European Journal of Palliative Care* 1998; 5: 117-120.

Thorpe G, Experiments on the dying. In: Williams CJ (ed.), *Introducing new treatments for cancer: practical, ethical and legal problems.* Chichester: John Wiley and Sons; 1992: 217-225.

Truog RD, Berde C, Mitchell C, Grier H, Barbiturates in the care of the terminally ill. *New England Journal of Medicine* 1992; 327: 1678-1682.

Twycross RG, Choice of strong analgesic in terminal cancer. Diamorphine or morphine? *Pain* 1977; 3: 93-104.

Twycross R, Where there's hope there's life. A view from the hospice. In: Keown J (ed.), *Euthanasia examined. Clinical and legal perspectives.* New York: Cambridge University Press; 1995: 141-168.

Twycross RG, *Introducing palliative care.* Oxford: Radcliffe Medical Press; 1996.

Valverius E, Le cure palliative in Svezia. *Bioetica e Cultura* 1999; 8: 33-44.

Van Boxtel T, *Infuustechnologie.* Houten: Bohn Stafleu van Loghum; 2000.

Van Dam H, Palliatieve zorg en euthanasie. Valse tegenstellingen. *Trouw* (Dutch newspaper), April 4, 1997.

Van den Akker B, Janssens MJPA, ten Have HAMJ, Euthanasia and international human rights law. Prolegomena for an international debate. *Medicine Science and the Law* 1997; 37: 289-295.

Van den Berg HJ, *Medische macht en medische ethiek.* Nijkerk: Callenbach; 1969.

Van den Berg HJ, *Leven in meervoud. Een metabletisch onderzoek.* Nijkerk: Callenbach; 1959.

Van den Toorn S, Pijnonderzoek. Resultaten in kaart gebracht. *Mediator* 2000; 11(1): 31-33.

Van der Wal G, Van der Maas PJ, *Euthanasie en andere medische beslissingen rond het levenseinde.* Den Haag: SDU; 1996.

Van der Wal G, van der Maas PJ, Bosma JM, Onwuteaka-Philipsen BD, Willems DL, Haverkate I, Kostense PJ, Evaluation of the notification procedure for physician-assisted death in the Netherlands. *New England Journal of Medicine* 1996; 335**:** 1706-1711.

Van der Maas PJ, van der Wal G, Haverkate I, De Graaff CLM, Kester JGC, Onwuteaka-Philipsen BD, et al. Euthanasia, physician-assisted suicide, and other medical practices involving the end of life in the Netherlands, 1990-1995. *New England Journal of Medicine* 1996; 335**:** 1699-1705.

Van Duijn N, Hospices zijn een noodzakelijk voorbeeld. *Pallium* 1999; 1: 16-17.

Van Duijn N, Zorgen voor 'slechte' mensen. *Pallium* 2000; 2: 18-20.

Van Hooijdonk AS, Van genezen via zorg naar liefdevolle aandacht. *Pallium* 1999; 1: 17.

Van Schaik F, Eerste hospice in Nederland op experimentele basis. *Tijdschrift voor Huisartsgeneeskunde* 1994; 11: 456-460.

Van Tongeren PJM, Ethiek en praktijk. *Filosofie en Praktijk* 1988; 9: 113-127.

Van Willigenburg Th, *Inside the ethical expert. Problem solving in applied ethics.* Kampen: Kok Pharos; 1991.

Veatch RM, Spicer CM, Medically futile care. The role of the physician in setting limits. *American Journal of Law and Medicine* 1992; 18: 15-36.

Vedder AH, *The values of freedom.* Utrecht: Brouwer Uithof; 1995.

Ventafridda V, Ripamonti C, De Conno F, Tamburni M, Cassileth BR, Symptom prevalence and control during cancer patients' last days of life. *Journal of Palliative Care* 1990; 6: 7-11.

Verhagen EH, Eliel MR, De Graeff A, Teunissen SCCM, Sedatie in de laatste levensfase. *Nederlands Tijdschrift voor Geneeskunde* 1999; 143: 2601-2603.

Verwey K, Baar FPM, Aghina MJFE, *Verpleeghuizen in de keten van palliatieve en terminale zorg.* Utrecht: Nederlandse Vereniging voor Verpleeghuiszorg; 1998.

Vrancken AME, *Chronische pijn. Het kruis van de geneeskunde.* Alblasserdam: Haveka; 1990.

Welie JVM, Authenticity as a foundational principle of medical ethics. *Theoretical Medicine* 1994: 15; 211-225.

Welie JVM, *In the face of suffering. The philosophical-anthropological foundations of clinical ethics.* Omaha: Creighton University Press; 1998.

Wilkes E, On withholding nutrition and hydration in the terminally ill. Has palliative medicine gone too far. A commentary. *Journal of Medical Ethics* 1994; 20: 144-145.

Wils JP, *Sterben. Eine Ethik der Euthanasie.* Paderborn: Schöning; 1999.

Wils JP, Pijn en identiteit. Een fenomenologische verkenning. In: Uerz I (ed.), *Pijn.* Nijmegen: Nijmegen University Press; 1996: 81-99.

Wilson WC, Smedira NG, Fink C, McDowell JA, Luce JM, Ordering and administration of sedatives and analgesics during the withholding and withdrawal of life support from critically ill patients. *Journal of the American Medical Association* 1992; 267: 949-953.

Working group on palliative care and the Association for Oncological nurses. Unpublished, 1996.

World Health Organisation, *Cancer pain relief and palliative care.* Geneva: Technical Report Series 804; 1990.

World Medical Association, *Declaration of Helsinki IV.* Hong Kong: World Medical Association; 1989.

ZON, *Jaarverslag ZON i.o. over het jaar 1996.* Den Haag: Oranje van Loon; 1997.

Zwart HAE, *Ethische consensus in een pluralistische samenleving. De gezondheidsethiek als casus.* Amsterdam: Thesis Publishers; 1993.

Zwart HAE, *Weg met de ethiek? Filosofische beschouwingen over geneeskunde en ethiek.* Amsterdam: Thesis Publishers; 1995.

Zwart HAE, De natuur als criterium voor medisch handelen. In: Keulartz J, Korthals M (eds.), *Museum aarde. Natuur: criterium of constructie?* Amsterdam: Boom; 1996a: 155-165.

Zwart HAE, Wat is observeren? Over natuurlijkheid in de geneeskunde. *Tijdschrift voor Geneeskunde en Ethiek* 1996b; 6: 45-50.

Zwart HAE, De spreekbevoegdheid van ethici. *Filosofie en Praktijk* 1998; 4: 184-201.

Zylicz Z, Hospice in Holland. The story behind the blank spot. *The American Journal of Hospice and Palliative Care* 1993; 4: 30-34.

Zylicz Z, Ondersteuning van de thuiszorg voor terminale patiënten: Hospice Rozenheuvel. *Medisch Contact* 1994: 49; 139-140.

Zylicz Z, The Netherlands: Status of cancer pain and palliative care. *Journal of Pain and Symptom Management* 1996; 12**:** 136-138.

Zylicz Z, Janssens MJPA, Options in palliative care. Dealing with those who want to die. *Baillère's Clinical Anaesthesiology* 1998; 12: 121-131.

SUMMARY

The key argument of this study is that the concept of palliative care is in need of critical, philosophical and theological analysis. In the beginnings of the development of palliative care, the scope was limited to the terminal phase. The demarcation of palliative care from other medical practices was relatively unproblematic since hospice caregivers chose to leave the formal health care structures out of a moral discomfort with the situation of the dying in the hospitals. Moreover, palliative care was firmly linked with cancer care. The religiously inspired values of palliative care were shared and so was the norm that active termination of life should not be part of palliative care. At the same time, paradoxically, the motive of the hospice movement has always been to re-integrate its philosophy into the mainstream health care system.

Overseeing recent developments of palliative care in Europe, it is safe to conclude that time is considered ripe for palliative care to become an integrated part of a variety of medical practices. This is on the one hand symptomatic for the maturation of palliative care. On the other hand it has increased the ambiguity and ambivalence of the concept of palliative care. Palliative care is now said to begin from the time of diagnosis. It is acknowledged that, apart from cancer patients, many other categories of patients are in need of palliative care. This makes the demarcation of palliative care from other medical practices problematic. Palliative care is no longer based on religious values and ethical debates on medical decision-making at the end of life reflect dissension. Many caregivers, especially in the Netherlands, do not exclude euthanasia from palliative care. The integration process of palliative care into the mainstream health care structures, has made the concept of palliative care unclear. This unclarity is the starting point of this study.

In chapter 1, an account is given of an appropriate ethical theory that is relevant for palliative care practice. It is argued that the dominant form of medical ethics lacks this practical relevance, focused as it is on problem-solving in the context of curative practices. For an ethics to be relevant for palliative care, it is imperative to re-introduce philosophical and theological theory. Only a medical ethics that is solidly based on philosophy or theology, only a medical ethics that adopts a critical distance from medical practice, is able to reveal the particularity of dominant discourses and to introduce new meanings taken from other, forgotten discourses. Thus, ethics can contribute to a sensitisation of the experiences of caregivers in the field. New orientations for concrete acts are

allowed to emerge. And new perspectives on palliative care practice can be proposed.

In chapter 2, the concept of palliative care as it is currently understood is reflected upon from an historical perspective. It is argued that an 'historical detour' can provide insight in the original motivations of palliative care and that these motivations are important since they can enrich current views on palliative care. When Cicely Saunders founded the first modern hospice (St Christopher's) she herself referred back to the hospices that were developed in the early Christian era. St Christopher's was also clearly situated in an earlier tradition of hospices many of which were established around 1900. Whereas Cicely Saunders stressed the continuity, there is also reason to stress discontinuities. For instance, the idea that pain and symptom control are primarily important because they ease spiritual reconciliation (an idea that was central to the early hospices for the dying) has been abandoned now. Based on the historical detour, it is argued that at least two aspects of palliative care are essential. First, palliative care should be considered as total care, stressing the importance not only of physical pain relief but also of psychological, social and spiritual pain relief. Second, the acceptance of death, present in the maxim that nothing should be done to hasten or postpone death in palliative care, is essential. Palliative care is said to stand in the middle of disproportionate life prolonging measures on the one hand and active euthanasia on the other. Chapter 2 ends with an overview of more empirical dimensions of palliative care. Organisational and conceptual differences are analysed in order to stress the novelty of the ambivalence of the concept of palliative care.

Chapter 3 discusses empirical findings on conceptual and ethical aspects of palliative care. The results of a large scale survey that was sent to over 2000 European professionals of palliative care are described and analysed. The majority of these professionals hold that palliative care starts from the time of diagnosis. Palliative care should be integrated within the mainstream health care system but without loosing a set of values that is said to be specific for palliative care. The danger that palliative care becomes medicalised is real according to just over half of the respondents. Medicalisation threatens that what is at the heart of palliative care namely the idea that medical, psychological, social and spiritual care are of equal importance. Notions that are considered most important for palliative care are quality of life, human dignity, acceptance of mortality and total care. Assumably, these notions reflect something of the moral specificity of palliative care. The norm that euthanasia can in extreme circumstances be part of palliative care is adhered to by not more than 5 % of the respondents. Remarkably, 15 % hold that the intentional shortening of life by

raising opioid doses can be part of palliative care whereas 36.5 % can conceive of situations in which medical treatment is withheld or withdrawn with the intention to shorten the life of the patient. Apparently, a substantial number of respondents do not consider intention crucial for the morality of a life shortening act.

Chapter 4 has come forth out of an analysis of the Dutch debate on palliative care. Palliative care is currently at the focus of interest in the Netherlands and further developments are expected to take place. There is a consensus that the quality of life of the patient and his or her loved ones is crucial for palliative care. It is agreed upon that palliative care is interdisciplinary, total care. However, if one follows the debates in the literature, disagreements on palliative care seem to be central. Disagreements that are under debate relate to the scope of palliative care, the organisational context best suitable to provide palliative care, the history of palliative care, the moral language of palliative care and, finally, to the question of euthanasia. Debates on euthanasia among palliative care practitioners do not only concern the morality of the act itself. Also, and perhaps more importantly, the quality of palliative care is central. Opponents argue that once the door stands open for euthanasia, palliative care practitioners will become less creative in their search for alternative palliative modalities. Allowing euthanasia thus leads to less quality of palliative care. This is refuted by 'proponents' who argue that the quality of palliative care is not diminished by including euthanasia in palliative care as a means of last resort. Empirical evidence is hard to find in this matter. It is concluded that there is reason for optimism if one oversees the developments in the Netherlands. Debates on palliative care are in need of a re-orientation towards the internal goal of palliative care, i.e. the quality of life of the patient and his or her loved ones. Then, it will appear that a larger consensus exists on palliative care than appears from the often polarised debates.

Chapter 5 discusses the notion of pain from a phenomenological perspective. For a long time, pain has been situated within a dualistic biomedical paradigm. In this model, pain is a sensation that is caused by external stimulations. Medical interventions are required to remove it. Alternative views of three Dutch philosophers from the phenomenological tradition (Buytendijk, Van den Berg, Metz) are analysed in order to formulate a critique on the biomedical paradigm and to introduce alternative understandings. Buytendijk has argued that pain can provide meaning in life. Van den Berg has confronted our current impoverished understanding of pain with other understandings from the past. Metz stressed that (chronic) pain can only be explained if it is situated in the intimate social sphere of the pain sufferer. Since the beginning of the

1990s, the interest in pain and pain treatment has increased. Many have interpreted pain as an experience that allows meaning to occur. In the debates on chronic benign pain, broader perspectives have emerged. The debates on cancer pain have benefited from the input of the hospice movement stressing not only the medical, but also the psychological, social and spiritual aspects of pain. Recently, it has been argued that the concept of total pain still carries traits of the dualistic Cartesian biomedical paradigm. Thus new narrative approaches towards pain are proposed and attention is drawn to realms of life in which pain is not stripped of its meaning. Chapter 5 concludes that relief of *the pain of medicine*, i.e. the inability of medicine to bring new, non-dualistic models of pain into practice, is one of the important challenges medicine faces in the future.

Chapter 6 draws attention to three notions that are not often used in the debates on palliative care: medical restraint, authenticity and hope. They are proposed because they are helpful in articulating the concept of palliative care. With regard to the medical realm, the notion of medical restraint is proposed because it implies the acknowledgement of the boundaries of medicine and because it implies that the medical realm of palliative care co-exists with other realms that are equally important. The notion of authenticity is proposed as an alternative for the notion of autonomy. The notion of autonomy has been part of a medical ethics that wanted to secure patients' interests against the power of the physician. Such a discourse is at odds with palliative care practice because it is based on mistrust. The notion of authenticity provides an alternative because it renders account of our dependency and fragility (characteristic for all of us but for the dying in specific) and because, unlike autonomy, it stresses that real choices are choices in character; real choices fit to a person's unique personality. Because the notion of authenticity, as it was developed in the existentialist tradition, cannot well render account of spirituality, it is argued that it should be paired with the notion of hope. Hope is an existential category. Without it we cannot live. It can relate to obtainable objects but hope can also relate to questions of ultimate importance, i.e. to eschatology. And especially in the direct confrontation with death, these questions urge themselves upon us. What's more, it is our mortality that makes an eschatology possible.

Chapter 7 results from a participant observation study in one of the hospices in the Netherlands. It begins with a short description of the hospice movement in the Netherlands. Then, with the help of four case studies, medical decisions directly or indirectly relating to euthanasia are examined. Euthanasia is not carried out in the hospice but if patients want, they can be transferred to a nearby hospital where they can have euthanasia carried out (self-evidently under

conditions). While 25 % of the patients admitted in the hospice request for euthanasia at a given time, it hardly ever happens that patients hold on to their request and are transferred to the hospital. Apparently, in the context of good care, the vast majority of euthanasia requests disappear. One case describes a homeless man who suffered from excruciating physical pain. The caregivers suffered with him and began to feel burnt out after some time. The decisions that were taken to decrease his pain perfectly match the demands of the doctrine of double effect. But the caregivers felt they had failed. An important conclusion of chapter 7 is that everyday practice is different from ethical logic.

Chapter 8 draws attention to a subject that has not been given much attention in the Netherlands: the subject of terminal sedation. Three positions that can be found in the literature are analysed. The first position is adhered to by the majority of caregivers (see chapter 3) and holds that terminal sedation can be a means of last resort in palliative care but euthanasia cannot. The second position holds that in some cases, euthanasia can be part of palliative care, even though terminal sedation is to be morally preferred. A third position holds that terminal sedation is morally indifferent from euthanasia and that both acts can be part of palliative care. Subsequently, it is argued that the last position is untenable since (1) intentions are relevant for the morality of actions and since (2) the taking of another person's life is at least wrong at first sight. The chapter continues to argue that based on these two grounds terminal sedation can serve as a good alternative for euthanasia even though hard cases can be conceived of in which patients do not want to die under heavy sedation. In such cases, the autonomy of the patient can never be the only reason to meet a request for euthanasia. Concludingly, it is argued that patients who want euthanasia carried out should be informed of the alternative of terminal sedation. For some, terminal sedation may be preferable to euthanasia. Therefore, the issue deserves more attention than it has received thus far in the Dutch debates.

Chapter 9 examines the morality of clinical trials in palliative care. Can clinical trials be a part of palliative care at all? Certainly, when patients are about to die, they should not engage in such trials. But when death is still relatively far ahead, patients may want to participate. At first sight, clinical trials put that at risk what is essential for palliative care namely the best possible quality of life of patients and loved ones. Participation in trials carries with it the risk of severe physical, emotional, social and spiritual harms. The question whether the imperative to improve care for future patients excludes the imperative to provide the best of care for current patients is answered negatively. Again, the notions of authenticity and hope are analysed in order to argue that for some patients, not all, participation in clinical trials may be a

meaningful enterprise. In helping the treatments of future patients improve, their lives may gain meaning. Thus, clinical trials need not be excluded from palliative care.

The conclusion of this study focuses on four challenges palliative care faces in the future. First, more research needs to be conducted in possible demarcations of palliative care from other medical practices. If one considers the results of the survey that was discussed in chapter three, meeting this challenge is for an important part an ethical task. More research needs to be conducted in articulating and evaluating the moral specificity of palliative care. Second, through input of philosophy, theology and history, the particularity of current discourses need to be brought to the surface. Room should be given for new perspectives on palliative care. In the debates on palliative care, the meaning of notions that are used is too often taken for granted. They are in need of philosophical and theological reflection with the help of which other, broader meanings that have become forgotten may be re-introduced. Also notions that have been central in the past but have been forgotten in the current discourses, may be potentially relevant. Thus, a richer understanding of palliative care can be developed. A third challenge palliative care faces has to do with moral dilemmas. Two issues are pointed out (acknowledging that many more moral dilemmas that occur in everyday practice should also be subject to analysis). First, the debates on euthanasia need to be broadened, stressing alternative palliative modalities and assessing what patients really mean when they request for euthanasia. Second, the international debates should become more open. In pluralistic societies, different opinions should be allowed to co-exist, also in the area of palliative care. A fourth challenge palliative care faces has to do with perspectives on human mortality, a topic that was marginally addressed in chapters 6 and 9. It is argued that in everyday life we cannot but disregard death to a certain extent. In the face of mortality, our everyday concerns appear meaningless. At the same time, paradoxically, in the direct confrontation with the death of a loved one, the eschatological questions of ultimate importance urge themselves upon us. It is argued that palliative care has been both symptomatic and stimulative for recent changes in our attitudes towards death. Death is more in the open. Furthermore, many acknowledge that the direct confrontation with a loved one's death provides us with opportunities to give and receive meaning in life. The fourth challenge for palliative care is thus to further stimulate new ways of dealing with death and dying, acknowledging that it is our mortality that enables us to give and receive meaning.

SAMENVATTING

In deze studie wordt beargumenteerd dat het concept palliatieve zorg kritische, filosofische en theologische analyse behoeft. In de beginfase van de moderne palliatieve zorg was de reikwijdte van het concept beperkt. Palliatieve zorg was terminale zorg. Palliatieve zorg was ook relatief helder onderscheiden van andere medische praktijken. De hospicebeweging koos er immers voor om het formele gezondheidszorgsysteem te verlaten vanuit een moreel onbehagen dat voortkwam uit de wijze waarop in de ziekenhuizen met stervende patiënten werd omgegaan. Bovendien werd palliatieve zorg met name opgevat als zorg voor kankerpatiënten. De categorie patiënten die palliatieve zorg ontving was dus eveneens helder afgebakend. De zorgverleners in de eerste moderne hospices deelden het religieus geïnspireerde waardepatroon waarop de hospicebeweging was gestoeld en er bestond consensus over de norm dat euthanasie geen deel mocht uitmaken van palliatieve zorg. Tegelijkertijd was de intentie van deze zorgverleners van het eerste uur om 'hospice' (opgevat als "filosofie van zorg") te herintegreren in de gezondheidszorg.

Als we de recente ontwikkelingen op het gebied van palliatieve zorg in Europa bezien, kunnen we concluderen dat momenteel de tijd rijp wordt geacht om palliatieve zorg verder te integreren zodat het een onderdeel wordt van uiteenlopende medische praktijken. Aan de ene kant is deze ontwikkeling symptomatisch voor het rijpingsproces dat palliatieve zorg doormaakt. Aan de andere kant heeft ze geleid tot een toenemende onhelderheid en meerduidigheid van het concept palliatieve zorg. Palliatieve zorg begint volgens de meeste zorgverleners vanaf het moment van de diagnose (bewijs hiervoor wordt in hoofstuk 3 gegeven). De exclusieve associatie met zorg voor kankerpatiënten kan niet meer worden verondersteld. Veeleer wordt erkend dat er vele andere categorieën patiënten zijn die eveneens behoefte hebben aan palliatieve zorg. Dit maakt de demarcatie van palliatieve zorg ten opzichte van andere medische praktijken problematisch. Palliatieve zorg is inmiddels een geseculariseerde praktijk en de ethische debatten rondom medische beslissingen aan het levenseinde laten belangrijke meningsverschillen zien. Veel zorgverleners, met name in Nederland, sluiten euthanasie niet bij voorbaat uit van palliatieve zorg. De nog immer toenemende integratie van palliatieve zorg in de gezondheidszorg heeft het concept onhelder gemaakt. Deze onhelderheid kan gezien worden als het centrale uitgangspunt van dit onderzoek.

In hoofstuk 1 wordt rekenschap afgelegd van een passende ethische theorie die praktisch relevant is voor de palliatieve zorg. Beargumenteerd wordt dat de dominante vorm van medische ethiek, welke zich met name bezig houdt met het oplossen van morele dilemma's in curatieve praktijken, deze praktische relevantie ontbeert. Wil ethiek relevant zijn voor palliatieve zorg, zal filosofische en theologische theorievorming geherintroduceerd moeten worden. Slechts een ethiek die zich verstaat als een onderdeel van de theologie of de filosofie, met andere woorden, slechts een ethiek die een kritische distantie betracht ten opzichte van praktijken, is in staat om de particulariteit van het gevestigde discours te onthullen en nieuwe betekenissen uit andere, vergeten discoursen voor te stellen. Op deze wijze draagt ethiek bij aan een sensibilisering van de ervaringen van zorgverleners. Nieuwe orientaties voor concreet handelen dienen zich aan. En nieuwe perspectieven op palliatieve zorg kunnen ontwikkeld worden.

In hoofdstuk 2 wordt nagedacht over conceptuele aspecten van palliatieve zorg vanuit een historisch perspectief. Beargumenteerd wordt dat een 'historische omweg' inzicht kan verschaffen in de oorspronkelijke motivaties van de palliatieve zorg. Deze motivaties uit het verleden kunnen ons huidig verstaan verrijken. Cicely Saunders heeft tijdens de ontwikkeling van haar eerste professionele hospice (St Christopher's) zelf terugverwezen naar de allereerste hospices die ontstonden in de vroegchristelijke tijd. Bovendien maakte St Christopher's deel uit van een reeds bestaande hospicebeweging die was ontstaan aan het einde van de 19^{e} eeuw. Maar terwijl Cicely Saunders met name de continuïteit in de geschiedenis van de hospices benadrukte, kunnen eveneens discontinuïteiten waargenomen worden. De nadruk op spirituele zorg van de eerste *hospices for the dying* waarbij bijvoorbeeld pijn en symptoomcontrole als middel werd gezien om spirituele verzoening te vergemakkelijken, wordt niet meer gedeeld. Op grond van de historische omweg wordt in dit hoofdstuk verder beargumenteerd dat tenminste twee aspecten cruciaal zijn voor palliatieve zorg. Ten eerste is palliatieve zorg altijd 'totale zorg' in de zin dat niet enkel de verlichting van fysieke pijn centraal staat maar ook de verlichting van emotionele, sociale en spirituele pijn. Ten tweede is de acceptatie van sterfelijkheid essentieel, zoals bijvoorbeeld verwoord in de maxime dat niets gedaan wordt om de dood te verhaasten noch om de dood verder uit te stellen. Palliatieve zorg, zo wordt beweerd, staat in het midden tussen een disproportionele inzet van middelen om genezing of levensverlenging te bereiken enerzijds en actieve levensbeëindiging anderzijds. Het hoofdstuk eindigt met een kort overzicht van meer empirische dimensies van palliatieve zorg. Organisatorische en conceptuele verschillen worden geanalyseerd om de

meerduidigheid van palliatieve zorg (een meerduidigheid die recent is) aan het licht te brengen.

In hoofdstuk 3 wordt een empirisch onderzoek naar ethische en conceptuele aspecten van palliatieve zorg beschreven. De resultaten van een vragenlijst die naar meer dan 2000 Europese actoren in het veld van de palliatieve zorg is gestuurd, worden er geanalyseerd. De meerderheid vindt dat palliatieve zorg begint bij de diagnose. Palliatieve zorg zou volledig geïntegreerd moeten worden in de gezondheidszorg, echter zonder een specifiek waardenpatroon daarbij te verliezen. Het gevaar dat palliatieve zorg steeds meer gemedicaliseerd raakt, wordt onderkend door een kleine meerderheid. Medicalisering brengt de kern van de palliatieve zorg in gevaar namelijk het uitgangspunt dat medische, psychologische, sociale en spirituele zorg van even groot belang zijn. Morele noties die het meest belangrijk worden geacht zijn: kwaliteit van leven, menselijke waardigheid, acceptatie van sterfelijkheid en totale zorg. We mogen aannemen dat deze noties iets onthullen van de morele specificiteit van palliatieve zorg. De norm dat euthanasie in extreme omstandigheden deel kan uitmaken van palliatieve zorg wordt door niet meer dan 5 % van de respondenten ondersteund. Opmerkelijk is dat intentionele levensverkorting door middel van toediening van hoge doses medicatie door 15 % wordt geaccepteerd. En niet minder dan 36,5 % van de respondenten sluit intentionele levensverkorting door middel van het staken of afzien van medische behandeling niet uit van palliatieve zorg. Blijkbaar is er een aanzienlijk aantal respondenten dat intentie niet cruciaal acht voor de moraliteit van een levensverkortende behandeling.

Hoofdstuk 4 is voortgekomen uit een analyse van het Nederlandse debat over palliatieve zorg. Palliatieve zorg in Nederland staat momenteel in de schijnwerpers en zal zich ook in de toekomst verder ontwikkelen. Er bestaat in de Nederlandse literatuur een consensus dat de kwaliteit van leven van de patiënt en diens naasten essentieel is voor palliatieve zorg. Palliatieve zorg is interdisciplinaire, totale zorg. Wanneer men echter kijkt naar de debatten valt op dat op belangrijke punten onenigheid bestaat. Gediscussieerd wordt over de reikwijdte van palliatieve zorg, de organisatie van palliatieve zorg, de geschiedenis van de Nederlandse palliatieve zorg, de morele taal van palliatieve zorg, en over euthanasie als onderdeel van palliatieve zorg. Ten aanzien van dit laatste debat moet opgemerkt worden dat niet enkel de moraliteit van euthanasie als zodanig op het spel staat. Ook, en misschien belangrijker, staat de kwaliteit van de palliatieve zorg op het spel. Tegenstanders van euthanasie beweren dat wanneer eenmaal de deur voor euthanasie openstaat, de creativiteit van de arts daardoor zal verminderen. Hij of zij zal minder snel op zoek gaan naar

mogelijke alternatieven. Toestaan van euthanasie lijdt tot een minder goede palliatieve zorg. Voorstanders beweren dat hun palliatieve zorg helemaal niet van mindere kwaliteit is doordat euthanasie niet bij voorbaat wordt uitgesloten. Bewijs voor beide stellingen is niet gemakkelijk aan te voeren. In dit hoofdstuk wordt geconcludeerd dat er reden voor optimisme is wanneer we de recente ontwikkelingen op het gebied van palliatieve zorg in Nederland bezien. De debatten in de media behoeven echter een herorientatie op het 'interne doel' van de palliatieve zorg, namelijk de kwaliteit van leven van de patiënt en diens naasten. Dan blijkt dat er meer consensus bestaat dan op het eerste gezicht het geval lijkt te zijn.

Hoofdstuk 5 analyseert de notie 'pijn' vanuit een fenomenologisch perspectief. Lange tijd werd pijn gesitueerd binnen een dualistisch biomedisch kader. Hierbinnen werd pijn opgevat als een gevoel dat door externe stimuli wordt veroorzaakt. De geneeskunde neemt de oorzaak van de pijn weg en de pijnsensatie zal verdwijnen. Drie alternatieve visies uit de fenomenologische traditie worden vervolgens besproken om een kritiek te kunnen formuleren op het biomedische paradigma en nieuwe verstaansmogelijkheden te kunnen introduceren. Buytendijk heeft gewezen op de mogelijkheid dat pijn aanleiding kan zijn voor zingeving. Van den Berg heeft ons huidige, verarmde, verstaan van pijn geconfronteerd met andere verstaansmogelijkheden uit het verleden. Metz heeft benadrukt dat (chronische) pijn enkel verklaard kan worden door de intieme sociale context van de pijnlijder erbij te betrekken. Sinds het begin van de jaren 90 neemt de interesse in pijn en pijnbestrijding toe. Velen hebben pijn geïnterpreteerd als een ervaring waaraan zin ontleend kan worden. In de debatten rondom chronisch benigne pijn zijn bredere perspectieven ontwikkeld. En de debatten rondom maligne pijn hebben kunnen profiteren van de inbreng van de hospicebeweging welke niet enkel de medische kant, maar eveneens de emotionele, sociale en spirituele kanten van pijn heeft benadrukt. Recentelijk is beargumenteerd dat het concept van 'totale pijn' nog immer karaktertrekken bevat van het Cartesiaanse dualistische denken. Nieuwe narratieve benaderingen worden voorgesteld en aandacht wordt gevraagd voor levensbereiken waarin pijn niet koste wat kost vermeden moet worden maar waarin pijn verschijnt als betekenisvol en aantrekkelijk. Hoofstuk 5 concludeert dat verlichting van de *pijn van de geneeskunde*, d.w.z. het onvermogen van de geneeskunde om niet-dualistische theoretische modellen concreet in praktijk te brengen, een belangrijke uitdaging is voor de geneeskunde in de nabije toekomst.

Hoofdstuk 6 vraagt aandacht voor drie noties die minder vaak in de debatten rondom palliatieve zorg gebruikt worden: medische terughoudendheid, authenticiteit en hoop. Deze worden hier voorgesteld omdat ze goed in staat zijn

de betekenis van het concept palliatieve zorg te verwoorden. Met betrekking tot het medische bereik van de palliatieve zorg wordt de notie van medische terughoudendheid voorgesteld omdat ze een aanvaarding van de grenzen van de geneeskunde veronderstelt. Tevens erkent ze dat medische zorg onlosmakelijk verbonden is met psychologische, sociale en spirituele zorg. De notie van authenticiteit wordt voorgesteld als alternatief voor het autonomieprincipe. Autonomie heeft deel uitgemaakt van een ethiek die patiëntenrechten wilde beschermen tegen de macht van artsen. Zulk een discours stemt niet overeen met de palliatieve zorg omdat het gebaseerd is op wantrouwen. Authenticiteit is een bruikbaar alternatief omdat het rekenschap aflegt van onze afhankelijkheid en kwetsbaarheid (karakteristiek voor ons allen, maar in het bijzonder voor ongeneeslijk zieken). Ook benadrukt authenticiteit, in tegenstelling tot autonomie, dat 'echte' keuzes, keuzes zijn die passen bij iemand's persoonlijkheid. Authenticiteit, zoals het ontwikkeld is binnen het existentialisme, kan echter moeilijk rekenschap afleggen van spiritualiteit. Daarom dient het gekoppeld te worden aan de notie hoop. Hoop kan betrekking hebben op concrete, bereikbare objecten. Maar het heeft ook te maken met vragen die in laatste instantie van levensbelang zijn, met andere woorden, hoop heeft ook te maken met eschatologie. Met name in de directe confrontatie met het sterven van een geliefde naaste dringen zulke vragen zich aan ons op. Sterker nog, onze sterfelijkheid vormt de mogelijkheidsvoorwaarde voor het stellen van zulke vragen.

Hoofstuk 7 is voortgekomen uit een participerende observatie in één van de Nederlandse hospices. Het begint met een korte beschrijving van de Nederlandse hospicebeweging. Vervolgens worden, met behulp van vier casusanalyses, enkele medische beslissingen die direct of indirect betrekking hebben op euthanasie geanalyseerd. Euthanasie wordt in het hospice niet toegepast maar als patiënten willen, kunnen ze overgebracht worden naar een nabij ziekenhuis waar euthanasie, onder voorwaarden natuurlijk, wel toegepast wordt. Terwijl 25 % van de patiënten op enigerlei moment een euthanasieverzoek uit in het hospice, gebeurt het bijna nooit dat deze patiënten bij hun verzoek blijven en uiteindelijk door euthanasie sterven. Blijkbaar verdwijnt het overgrote deel van de verzoeken door middel van goede zorg. In één casus wordt een thuisloze man beschreven die leed aan ondraaglijke, fysieke pijn. De zorgverleners raakten hierdoor opgebrand. De beslissingen die vervolgens genomen werden om de pijn van de man te verlichten corresponderen aan de vereisten die het principe van dubbel effect stelt. Toch hadden de zorgverleners het gevoel gefaald te hebben. Een conclusie die uit dit

hoofdstuk wordt getrokken is dat de alledaagse praktijk van de palliatieve zorg verschilt van ethische logica.

Hoofdstuk 8 vraagt aandacht voor een thema dat nog niet veel aandacht heeft gekregen in de Nederlandse debatten: terminale sedatie. Drie posities die in de literatuur te vinden zijn worden uiteengezet. De eerste positie wordt door de meerderheid van Europese palliatieve zorgverleners onderschreven (zie hoofdstuk 3) en stelt dat terminale sedatie een laatste redmiddel kan zijn en euthanasie niet. De tweede positie stelt dat euthanasie een laatste redmiddel kan zijn maar dat op morele gronden terminale sedatie de voorkeur heeft. Een derde positie stelt dat terminale sedatie vanuit moreel perspectief op hetzelfde neerkomt als euthanasie. Vervolgens wordt beargumenteerd dat de laatste positie onhoudbaar is omdat (1) intenties relevant zijn voor de moraliteit van ons handelen en (2) het doden van iemand tenminste op het eerste gezicht een moreel kwaad is. Op grond van deze twee aannames moet worden beargumenteerd dat terminale sedatie een goed alternatief vormt voor euthanasie alhoewel tragische casus voorstelbaar zijn wanneer een patiënt bijvoorbeeld niet onder sedatie wil sterven. De autonomie van de patiënt kan in zulke casus niet de enige reden vormen voor euthanasie. Geconcludeerd wordt dat patiënten die verzoeken om euthanasie tenminste geïnformeerd zouden moeten worden over de alternatieve mogelijkheid van terminale sedatie. Sommigen zullen terminale sedatie prefereren boven euthanasie. Daarom verdient dit thema meer aandacht in de debatten dan dat het tot nu toe heeft gekregen.

Hoofdstuk 9 onderzoekt de moraliteit van klinisch experimenteel onderzoek in de palliatieve zorg. Kan zulk onderzoek überhaupt deel uitmaken van palliatieve zorg? Het moge duidelijk zijn dat patiënten in de terminale fase niet voor zulk onderzoek in aanmerking komen. Maar als de dood nog relatief ver weg is, kunnen er patiënten zijn die met zulk onderzoek mee willen doen. Op het eerste gezicht brengt deelname aan klinisch experimenteel onderzoek precies dat in gevaar wat cruciaal is voor palliatieve zorg, namelijk het welzijn voor de patiënt en diens naasten. Ernstig lichamelijk, emotioneel, sociaal en spiritueel lijden kan worden veroorzaakt door deelname. De vraag is of de morele imperatieven om enerzijds de behandelingsmogelijkheden voor toekomstige patiënten te verbeteren en anderzijds goede zorg voor huidige patiënten te verlenen elkaar niet uitsluiten. Beargumenteerd wordt dat dit niet het geval hoeft te zijn. Opnieuw worden de noties van authenticiteit en hoop geanalyseerd om te laten zien dat voor sommige, niet alle, patiënten deelname aan een klinisch experimenteel onderzoek een zinvolle aangelegenheid kan zijn. Door te helpen de behandelingsmogelijkheden voor toekomstige patiënten te

verbeteren kan hun leven als zinvol worden ervaren. Klinisch experimenteel onderzoek hoeft dus niet uitgesloten te worden van de palliatieve zorg.

De conclusie van deze studie vat vier uitdagingen voor palliatieve zorg in de nabije toekomst samen. Ten eerste dient meer onderzoek uitgevoerd te worden naar demarcaties van palliatieve zorg ten opzichte van andere medische praktijken. Als we de resultaten van de questionnaire bezien (zie hoofdstuk 3) kan geconcludeerd worden dat dit voor een belangrijk deel een ethische taak is. Tot op heden is de morele specificiteit van de palliatieve zorg nog onvoldoende gearticuleerd en geanalyseerd. Ten tweede dient de particulariteit van het huidige discours aan het licht gebracht te worden door middel van filosofische, theologische en historische inbreng. Er dient meer ruimte te komen voor nieuwe perspectieven op palliatieve zorg. In de huidige debatten blijft de betekenis van morele noties vaak onbereflecteerd. Ze behoeven echter filosofische en theologische reflectie opdat bestaande betekenissen beter kunnen worden gearticuleerd en andere relevante betekenissen, die ondergesneeuwd zijn geraakt, kunnen worden geherintroduceerd. Relevante noties die binnen andere discoursen betekenisvol zijn maar in de debatten over palliatieve zorg niet gebruikt worden, kunnen worden voorgesteld. Zo ontstaat een rijker verstaan van palliatieve zorg. Een derde uitdaging in de nabije toekomst heeft betrekking op morele dilemma's in de palliatieve zorg. Twee aspecten worden aangegeven (in het besef dat er in de alledaagse praktijk van de palliatieve zorg veel meer morele dilemma's zijn die vragen om analyse). Ten eerste zou het euthanasiedebat verbreed moeten worden. Alternatieve mogelijkheden dienen te worden benadrukt en zorgvuldig zou nagegaan moeten worden wat patiënten daadwerkelijk menen als ze vragen om euthanasie. Ten tweede dienen de internationale debatten over euthanasie opener te worden. In pluralistische samenlevingen mogen meerdere meningen naast elkaar bestaan, ook binnen de palliatieve zorg. Een vierde uitdaging voor palliatieve zorg betreft het stimuleren van nieuwe perspectieven op onze sterfelijkheid. Dit thema is slechts aangestipt in de hoofdstukken 6 en 9. In ons dagelijkse leven negeren we veelal het feit dat we sterfelijk zijn. Leven in het gezicht van de dood maakt onze dagelijkse zorgen zinloos en in zekere zin is dat ondraaglijk. Tegelijkertijd worden wij in de confrontatie met de dood van een geliefde geconfronteerd met vragen van levensbelang. De ontwikkeling van palliatieve zorg is tegelijkertijd symptomatisch en stimulerend voor een zich recentelijk aftekenende verandering in onze houding tegenover onze sterfelijkheid. De dood wordt openlijker bejegend. Velen erkennen dat de confrontatie met de dood mogelijkheden bevat voor spirituele groei. De vierde uitdaging voor de palliatieve zorg is een verdere stimulering van nieuwe omgangswijzen met dood

en sterfelijkheid in het besef dat onze sterfelijkheid de mogelijkheidsvoorwaarde is voor een zinvol bestaan.

Curriculum Vitae

Rien (Marinus Johannes Petrus Antonius) Janssens was born on October 19, 1969 in Waalre, the Netherlands. After completing secondary school (June, 1988) he studied theology at the Catholic University Nijmegen where he took his M.A. degree in 1996 (cum laude). In the same year, he started to work on his thesis as junior researcher at the department of Ethics, Philosophy and History of Medicine of the University Medical Center St Radboud, Nijmegen. From March 1998 until March 2001, he was the project manager of the European *Pallium* project on palliative care ethics.